



“TO TELL OR NOT TO TELL”

- Disclosing a psychiatric disability in the educational setting -



2.4.3 Disclosure

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Foreword

The information presented in this brochure is intended to support students with psychiatric disabilities in making informed decisions about whether or not to disclose. The brochure is also meant for student counsellors and relevant others who are involved with students with psychiatric disabilities.

The information in the brochure is based on the current literature about disclosure (see references) and on the experiences with the brochure of students and professionals from Norway, Portugal, the Czech Republic and the Netherlands.

To study successfully, it is important for students with a psychiatric disability to have some specific skills. One of these skills could be disclosing a psychiatric disability in the educational setting.

Susan.

Susan is 23 years old and a first year psychology student. At the age of 19, Susan became very depressed. She attempted suicide and was admitted to a mental hospital for some time. She has been in day treatment at the same mental health organization for the past two years. Over the last year Susan has been doing very well and she went back to study psychology again (at a different university). In an introductory meeting with the lecturer and other students, the lecturer asks Susan, "Susan, what have you done before?" Susan is surprised by the question and doesn't know what to say.

Peter.

Peter is 22 years old and at the point in his study at the university where he is to start a period of internship. He has an interview with a supervisor of the company where he wishes to do his internship. During the interview, the supervisor asks Peter why one year in his curriculum vitae is blank. Peter tells the supervisor that three years ago he was treated for a year because of a psychosis. The supervisor ends the interview quickly. Peter never heard from the company again.

Introduction

The stories of Susan and Peter are good examples of a very common dilemma for students with psychiatric disabilities: the decision to tell or not to tell about their psychiatric disability. Disclosure can have benefits, but some students tend not to disclose their psychiatric disability because they fear being discriminated against or because they are able to manage their study on their own. However, every student's situation can change for a variety of reasons and this may have an impact on their decision to disclose.

The decision to be open about a psychiatric disability is a personal one, and your own situation and circumstances play an important role in making this decision. Below, you'll find some aspects that may help you with your decision.

- Do I benefit from disclosure?
- Whom do I tell and why?
- How will teaching staff respond to students with psychiatric disabilities?
- Will I get better support if I disclose?
- What are the risks of disclosure?
- Will I be carrying the continuous stigma of having a psychiatric disability ("being mad")?
- What happens if people find out?
- What will people think of me?

In this brochure, the different aspects of disclosing your psychiatric disability are discussed. The information presented in this brochure is intended for students with psychiatric disabilities and for professionals who work with the students.

Disclosing your psychiatric disability

Disclosing your psychiatric disability means that you tell someone about your psychiatric past or present. To decide whether to tell about your psychiatric disability or not, you could consider the following steps:

Determine:

- 1 Whether** to tell
- 2 What** to tell
- 3 Who** to tell
- 4 When** to tell
- 5 How** to tell

It is important to note that you do not need to follow the steps in a specific order. You can start with the step you prefer. However, we recommend that you do consider all five steps to come to a well informed decision.

1. *Whether to tell*

The decision to disclose is a difficult one. The choice will be different for everyone because everyone has 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 has to live with the positive and negative outcomes.

A psychiatric disability is often not visible and manifests itself differently and in its own, unique way in each person. Disclosing your psychiatric disability can be necessary to get access to the accommodations and support the faculty offers to students with psychiatric disabilities. Disclosure can also be related to the decision to tell other students, in case of a friendship, or when you have to work together with others.

Unfortunately many myths and wrong information still exist regarding psychiatric illnesses. Disclosure can sometimes result in being stigmatized, with people treating you differently or viewing you as your illness, especially if they don't know anybody themselves with a psychiatric disability.

So, there are positives and negatives to disclosing your psychiatric disability. The decision to disclose or not is often not a final decision but one that can be re-evaluated over time, based on the student's circumstances. It is important that the factors that determine whether disclosure occurs or not be explored before a decision is made. In determining whether disclosure should occur or not, you could consider the following aspects.

Benefits of disclosing

- Better support
- Adjustments can be negotiated and implemented
- If staff respond positively, you may feel more confident about your studies.
- You might 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 psychiatric disabilities
- More interest, care and support from teaching staff
- Staff will be able to respond appropriately and sensitively when difficult situations occur
- Having access to the same rights and entitlements as everybody else
- Not being seen as a troublesome student
- Being able to receive support and advice

Disadvantages of disclosing

- Others may feel threatened, due to ignorance and personal experience
- The burden of having to explain your disability
- The fear of discrimination
- Feelings of rejection
- The fear of being singled out in class

- Misunderstanding by others of the disability's impact
- The belief that you may be denied opportunities, such as a place on the course you wish to undertake
- The fear that the disability may provoke curiosity or unnecessary concern in others
- Fear that the disability instead of the academic capacity of the person will become the central focus
- Fear that you will be treated differently from other students

You may also choose NOT to disclose your psychiatric disability

You may have several reasons for not disclosing, including:

- You may not require any additional support or services, because your disability does not influence your capacity to study at college
- You may be uncertain about contacting disability support services at this time
- You may not know who will have access to your personal information
- You may have developed strategies for managing your psychiatric disability and would not benefit from disclosing your disability
- You have an expectation that equity and access are in place, thus eliminating the need to seek education related adjustments

If you do not require any accommodations to perform your study, there is no reason to inform a college that you have a psychiatric disability.

Try to find a balance for yourself between the advantages and disadvantages about disclosure. You should be clear about why it is you want to disclose, what your goal is.

It is important that you make up your own mind and decide for yourself what is best for you.

2. What to tell

In every situation, with every person and at every moment, you have to ask yourself what you want to tell. You could have a fixed story that you tell every time again, but that story may not always be adequate.

According to the situation, you have to decide whether you want to tell about:

- Having a psychiatric disability
- Aspects of your psychiatric disability

What you tell can also vary depending on the person to whom you disclose. It could be that:

- You want to educate that person about your psychiatric disability
- You want to tell how your psychiatric disability impacts your study
- You want to explain that you have a certain learning style
- You want to provide the other person with information about your psychiatric disability

- You like to talk with a fellow student about your psychiatric disability

It is also possible that someone asks questions about your psychiatric disability—for example, a professor who asks what your diagnosis is when you ask him/her for support. What to do? In this situation, you are still the one who decides what and how much you tell about your disability. If you do not want to tell more than necessary, you could say, for example, the following:

The Disability Support Service has all the information. I would rather not discuss the details of my problems with you (alternative: I prefer to keep the details of my illness to myself), but my disability means that I have problems with (mention the study activity). Regarding this activity, the accommodation or support that helps me a lot is (mention the accommodation and/or support). I am happy to discuss with you how to realize this.

Explain your situation to your professor in such a way that he or she understands what the impact is of your disability on your study.

Most importantly, keep the disclosure conversation focused on your abilities, not on your disability. It is not always essential to disclose specific personal information about a disability. What is most important and helpful is to provide information about how the disability impacts your capacity to study and what support you need in order to study in an optimal environment.

3. Who to tell

Besides the decision whether and what to tell, it is also important to think about who to tell. Below you'll find a list of persons to whom you possibly want to disclose your psychiatric disability.

- *Academic advisor or counsellor.* He or she is there to help you to arrange things or refer you to the right services.
- *Special disability support staff.* The staff of disability support service is specialized in helping to arrange accommodations and to provide support.
- *Teaching staff,* because the accommodation or support you need is directly related to their course.
- *Fellow students,* so they understand why you are receiving accommodations or extra support and they can support you.
- *Faculty administrative staff,* because they can assist you with processing information or applications
- *Equity staff,* because they will assist you if you are being discriminated against or if you are not receiving the support to which you are entitled. They can also assist you if you are not sure to what support you are entitled.

- *Housemates*, so they understand for example why you use medication, why you go to bed so early or why you are feeling not so well.

Before you decide to disclose, often you want to know if the person will treat your information as confidential. Important in this decision are your experiences with earlier disclosures. If your trust has been abused in the past, you will think twice before you disclose again. This is discussed elsewhere in this brochure.

4. When to tell

Most educational programs have a time span of several years. In those years, many changes can occur. You'll find yourself in new situations, meet new people; there are changes in your circumstances, but also your study load at college could increase. All or any of these situations might be a catalyst to you needing to consider whether or not you disclose your psychiatric disability while studying.

Below you'll find a description of some of these situations.

Prior to enrollment

Your choice of a course of study at a certain college could be dependent on the support that the college offers to students with psychiatric disabilities, especially when you know that your psychiatric disabilities have influenced your prior study performances and that support is needed. To find out if the college provides academic and personal support, it is often necessary to disclose your psychiatric disability.

Therefore, it is necessary to decide whether you will need an accommodation or extra support to perform the study to which you are applying. The best way to do this is to find out what duties are required, and consider how you can fulfill them with or without an accommodation or extra support. This allows you to confidently decide whether or not to disclose your psychiatric disability. If you choose to be open because you need an accommodation or extra support, discuss the needed accommodation or support as soon as possible with disability service staff, because the process of enrolling can be exhausting with forms to complete, payments to be arranged, and venues to be located. Requesting support at an early stage can help you to start your study more relaxed and successfully.

Enrollment

Students with a disability are also faced with the choice of whether or not to disclose their disability at the time of enrollment. At the time of enrollment, often students have an opportunity to disclose their disability on the enrollment form. It is unlawful to use the disclosed information against you. The information is meant to discuss possible negative influences of your psychiatric disability on your study performance and/or to find solutions for these problems. If students choose not to disclose their disability on the enrollment form,

they still have the option of contacting the disability support service staff at any time for advice or practical support.

During your study

Some students tend not to disclose their psychiatric disability in the early stages of their study, sometimes out of fear of discrimination, and sometimes because they are able to manage their workload. However, every student's situation can change for a variety of reasons and this may influence their decision to disclose. It is also possible that during their studies, students unexpectedly acquire a psychiatric disability or experience a deterioration in an existing disability. This may result in the student needing to disclose the disability to seek support to continue the study. As these are unexpected circumstances, students may require disability support to be put in place quite quickly, to ensure that their studies are not negatively influenced. This may or may not be possible depending on the level of support required.

You may choose to disclose your disability at any time during your study because:

- Your personal circumstances may change—for example, you acquire a psychiatric disability.
- Your disability may progress and its impact on daily living may also increase.
- You may feel more confident that disclosing at this time will not lead to discrimination.
- You may have identified specific support that will enable you to participate in the course on an equal basis with other students.

In addition, in the following situations you may decide to disclose during your study:

- Before a specific exam.
- When you have to participate in a course in which a specific didactic method—for example, a role-play or working together in subgroups—is used.
- When you meet new people at the beginning of a new course.
- When you meet fellow students.
- When you become a member of a student group or student sports club.
- When you make new friends.

Internship or fieldwork

Most studies require an internship or fieldwork. Being an intern or working in the field often requires other skills, knowledge and attitudes than being a student at college. Most of the time you are seen as an employee and colleague instead of a student. It is possible that this new role asks for other accommodations and support. Also in this situation you will have to decide why, what and to whom you disclose your psychiatric disability in order to get the necessary accommodations and support. So, there are many moments and situations during your study in which you have to decide to disclose or not. It is and will always be your own decision to determine whether it is the right moment, the right situation and the right person, and how much information you wish to tell.

5. How to tell?

Disclosing your psychiatric disability is not a one-off event. Often, in every new situation (when), or with every new person you meet (who) you have to decide whether and what you want to tell about your psychiatric disability. Moreover, it is also important how you tell it. To prepare yourself for how to tell about your psychiatric disabilities, consider the following.

- Know yourself and your psychiatric disability.
- Identify your strengths.
- Identify areas where you may need assistance.
- Plan ahead and practice what you might say.
- Know the resources available to you.
- Know what you want to discuss with a disability liaison officer or counsellor.
- Become familiar with the equity policies and procedures of the school/university.
- Consider possible prejudices you may encounter and how to deal with them.
- Be prepared to deal with insensitive questions.

If you tell:

- Be brief.
- Relate what you tell to your study.
- Be assertive and enthusiastic.
- Be familiar with the topic and course requirements.
- Describe the way you learn most effectively.
- Discuss the reasonable adjustments you are requesting on the basis of your psychiatric disability.
- Describe how you overcome difficulties that the other person could see as problems.
- Be prepared to deal with insensitive questions.
- Before the meeting, determine a good time and place that you both agree on, to discuss your psychiatric disability.
- Depending on your preference, you can visit staff at their student consulting times, phone them, or e-mail them.
- Note that less effective or appropriate times and places are after lectures with other students listening, in the cafeteria, in a corridor, in the break of a lecture, etc.
- Find out as much as possible about how you are able to function and what the trigger points are to becoming unwell.
- Know about positive and adverse reactions to medicines, how they affect you and how this can influence your ability to study or enjoy being a student.

Sometimes you find it hard to be open about your psychiatric disability because you are still struggling to accept your situation. Also, when symptoms of your psychiatric problems occur (like depression, anxiety, fear or stress), it is often harder to be open about your

psychiatric disability. In these situations, it is good to talk with someone you trust and to consult him about whether to tell or not.

Confidentiality

An important consideration for you in your decision to disclose or not might be the issue of confidentiality, for example: 'If I disclose, then what will happen with this personal information?' If you want to disclose for academic or support purposes, it could be good to know if there are confidentiality policies at school/university about what happens with your personal information. You may want to find out about these policies before you decide to disclose. It is important to discuss what you and the other person mean by the term confidentiality.

In most circumstances, it is best practice that you are asked to give permission to pass the information to other persons or agencies. It may be necessary for you to notify tutors of the arrangements you have made with disability support staff. You may like to discuss with your disability support worker whether you feel comfortable with your tutors knowing about your psychiatric disability.

In case disclosure of a disability becomes a matter of duty of care, because your safety or that of others is at stake, then people who need to know may be informed without your permission. 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?

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

Discrimination

If you feel you have been discriminated against because of disclosing your psychiatric disability, you have the legal right to object. Please contact:

- The disability liaison officer at your institution
- The equity representative for your organization
- The discrimination advisor
- The student union
- The institution's grievance procedures
- The Equal Opportunity Commission
- The Human Rights and Equal Opportunity Commission

Disclosing your psychiatric disability

Worksheet 1

Instructions: Determine whether you want to tell about your psychiatric disability

Remember to:

- a. Identify benefits
- b. Identify risks
- c. Compare balance

Identify Whether to Tell	
A. What are the benefits of disclosing?	B. What are the disadvantages of disclosing?
C. Compare the benefits and the disadvantages. Which are most important to you? Rank the benefits and disadvantages of disclosing from most important to least important.	

Disclosing your psychiatric disability

Worksheet 2

Instructions: Think about your situation and decide what you want to tell.

Remember to:

- a. Assess your situation
- b. Determine what you want to tell

Formulate What to Say	
a. Assess your situation	
I have the following psychiatric disability/disabilities.	
This manifests itself in the following way.	
I find it hard to/ I have problems with (related to your study performance):	
I tell you this because:	
What would help me is:	
b. Determine what you want to tell	
Is everything that you wrote down under A relevant for the person you'd like to disclose to?	
Do you want to tell everything or only parts of it?	
Write down exactly what you want to tell.	

Disclosing your psychiatric disability

Worksheet 3

Instructions: Think about your own situation and identify who to tell.

Remember to:

- a. Brainstorm relevant people
- b. Select the best choice

Identify Who to Tell	
a. Brainstorm relevant people	
b. Select best choice (and your reasons).	

Disclosing your psychiatric disability

Checklist

Instructions: You could use this checklist when you are practicing disclosing, or when disclosing your psychiatric disability did not go well, in order to identify what went wrong or could go better. You can indicate which steps and behaviors you have performed, and you can reflect on this in the right column (comments). Discuss your performance, if needed, with, for instance, your disability specialist.

Disclosing your psychiatric disability	Yes	No	Partial	Comments
1. Choose whether to tell				
a. Identify benefits				
b. Identify disadvantages				
c. Compare and rank benefits and disadvantages				
2. Identify what you want to tell				
a. Assess your situation				
b. Determine what you want to tell				
3. Identify who to tell				
a. Brainstorm relevant people				
b. Select best choice				
4. Identify when to tell				
a. Identify times and places				
b. Choose best time and place				
5. Formulate how to tell				
a. Means of communication				
b. Tone of voice				

Further information

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 advisors.

Websites

Interesting information about studying for persons with psychiatric disabilities can be found on the websites below:

The Netherlands

www.begeleidieren.nl (in Dutch, with a page with information in English)

United States

<http://cpr.bu.edu/resources/reasonable-accommodations/jobschool>

An interactive and informative site with issues about work and school. The site is developed by the Centre for Psychiatric Rehabilitation of Boston University.

Canada

<http://www.cmha.ca/youreducation/introduction.html>

Information about studying with a psychiatric disability in higher education in Canada, with a special page on disclosure.

Australia

<http://www.hindawi.com/journals/edri/2014/295814/>

This is an article from the Latrobe University in Melbourne about the role of university support services on academic outcomes for students with mental illness.

England

[Oxford Student Mental Health Network](#)

This is a comprehensive site with information about mental health issues in Oxford, for students, teaching staff and mental health workers.

Colophon

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Project leader

Lies Korevaar, PhD.

Project coordinator

Jacomijn Hofstra, PhD.

Project members

Klára Bratršovská

Martin Fojtíček

Jacomijn Hofstra

Mette Kolbjørnsen

Lies Korevaar

Lúcia Oliveira

Luis Sá Fernandes

Evan Toft

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Information

Website: www.supportededucation.eu