

Studying with support serie

“TO TELL OR NOT TO TELL”

- Disclosing a psychiatric disability in the education setting -



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Forword

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

The information is based on the current literature about disclosure (see references) and compared and added with the experiences of students with psychiatric disabilities and directly involved Educational and Mental Health workers in the Netherlands. The brochure is also meant for student counsellors en relevant others who are involved with students with a psychiatric disability.

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 education setting".

Inez

Inez is 23 years old and first year college student Economy. At the age of 19 Inez became very depressed. She attempted suicide and has been 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. The last year Inez has been doing very well and she went back to study Economics again (at a different college). In an introduction meeting with other students, one of her fellow students asks her: "Yeh, what have you done before?". Inez is surprised by the question and doesn't know what to say.

Mark

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

Introduction

The stories of Inez and Mark are good examples of a very common dilemma for students with psychiatric disabilities: the decision to tell or not to tell about the psychiatric disability. Disclosure has benefits, but some students tend not to disclose their psychiatric disability, sometimes for fear of discrimination, and sometimes because they are able to manage their study. However, every student's situation can change for a variety of reasons and this may have impact on their decision to disclose. The decision to be open about the 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 who can help you with your decision:

- Do I benefit from disclosure?
- Whom do I tell and why?
- How will teaching staff respond do students with psychiatric disabilities?
- Will I be getting 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?

These, and other questions could appear to you. In this brochure the different aspects of disclosing your psychiatric disability are discussed. The information presented in this brochure is intended to help students with psychiatric disabilities (and relevant others) with their decision to tell or not to tell about their psychiatric disability.

Disclosing your psychiatric disability

"Disclosing your psychiatric disability" means that you tell someone about your psychiatric condition current and/or in the past.

To prepare yourself whether to tell about your psychiatric disability, 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*

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 will live with the positive and negative outcomes.

A psychiatric disability is often not visible and demonstrates 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.

The decision to disclose your psychiatric disability in the education sector is a personal choice for people with psychiatric disabilities. Disclosure is an individual decision, depending on the circumstances, the context and how comfortable the person feels about it.

Unfortunately many myths and wrong information remain regarding psychiatric illnesses. To disclose can sometimes result in being stigmatised with people treating you different or viewing you as an illness instead of being a person, especially if they don't know anybody themselves with a psychiatric disability.

There are therefore positives and negatives to disclosure of 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, students could consider the following aspects:

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 psychiatric disabilities
- to educate peers and/or teaching staff, to try to break down barriers or challenge stereotypes
- 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
- not being seen as a troublesome student
- being able to receive support and advice

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
- the believe you may be denied opportunities, such as a place in the course you wish to undertake
- the fear the disability may provoke curiosity or unnecessary concern in others
- fear that the disability will become the central focus in stead of the academic capacity of the person
- fear that you will be treated differently to 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 impact on your capacity to undertake study at college
- you may be uncertain whether to contact 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
- an expectation that equity and access are in place thus eliminating the need to seek education related adjustments

It is important to remember that if no accommodations are needed, or if you have made a decision to accommodate your potential needs personally (for example, by using a spell-check feature for English papers), then there is no need to disclose your disability.

If you do not require any accommodations to perform your study there is no reason to inform an college that you have a psychiatric disability. If you have a hidden psychiatric disability which does not affect your ability to perform your study you need not volunteer this information.

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.

Per situation you have to decide whether you want to tell about:

- having a psychiatric disability;
- which aspects of your psychiatric disability;

but it also could mean that you tell someone, because:

- you want to educate that person about your psychiatric disability;
- your psychiatric disability has an impact on your study;
- 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 request him for support. What to do? Also in this situation you are 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). In case of this activity, the accommodation or support that helps me a lot is (mention the accommodation and/or support). I like to consult you about how to realize this'.

Explain your situation to your professor, so he 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 student's disability impacts on their capacity to study and what supports are needed to assist in providing the optimum environment for study to occur.

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.

- If you need accommodations or support you could go to your academic advisor or counsellor first. He or she is there to help you to arrange things or he can refer to you to the right services.
- In most educational settings there are special disability support staff. The staff of disability support service is specialised in helping to arrange accommodations and to provide support.
- It is also possible that you have to tell a professor or other teaching staff, because the accommodation or support is directly related to their course.
- Fellow students you possibly like to inform, so they understand why you are receiving accommodations or extra support and so that they can support you.
- Faculty Administrative Staff, because they can assist you processing information or applications
- Equity staff, because they 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.
- Your housemates, if you share a home or flat with other students and if they ask you for example why you use medication, why you go to bed so early or if they notice your feeling unwell.

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

4. When to tell

Most educational programmes 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 loads at college could increase. All or any of these situations can 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 enrolment

Your choice for a study at a certain college could be depending on the support that college offers to students with psychiatric disabilities. Certainly 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 supports 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 accomplish this is to find out what duties are required, and consider how you can fulfil them with or without an accommodation or extra support. This will allow 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, venues to be located and finally lining up for that photo that adorns the student card. Requesting support in an early stage can help you to start your study more relaxed and could also mean a successful start of your study.

Enrolment

Students with a disability are also faced with the choice of whether or not to disclose their disability at the time of enrolment. At the time of enrolment students have an opportunity to disclose their disability on the enrolment form. It's unlawful to use the disclosed information against you, but is meant to discuss negative experiences with disclosing your psychiatric disability and/or to find solutions for your future study.

If students choose not to disclose their disability on the enrolment form, they still have the option of contacting the disability support service staff at any time to advise that they are enrolled and to seek information or practical support to assist with their studies.

During your study

Some students tend not to disclose their psychiatric disability in the early stages of their course, sometimes for 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 impact on their decision to disclose.

It is also possible for students at anytime during their studies to unexpectedly acquire a psychiatric disability or to experience a deterioration in an existing disability. This may result in the student needing to disclose their disability to seek support to continue their course. Occasionally, students disclose their disability at a time of crisis, because they did not anticipate potential issues or difficulties, which may arise in any course of study.

As these are unexpected circumstances, a student may require disability support to be put in place quite quickly, to ensure that they are not disadvantaged in their study. This may or may not be possible depending on the level of support required.

Students may choose to disclose their disability at any time during their studies because:

- their personal circumstances may change, such as a student acquiring a psychiatric disability
- a student's disability may progress and its impact on daily living may also increase

- a student may feel more confident that disclosing at this time will not lead to discrimination
- a student may have identified specific supports that will enable them to participate in their course, on an equal basis with other students

But also in the following situations:

- Before a specific exam.
- When you have to participate in a part of the course in which they use a specific didactic method, for example a role-play or that you have to work together in a subgroup
- When you need new people at the beginning of a new course
- When you meet fellow students
- When you become a member of a students' corps or students' sport club
- When you make new friends.

Internship or Fieldwork

Most studies require internship or fieldwork. Most of the time this highlights issues in relation to a psychiatric disability. Other skills, knowledge and attitude than at college. Most of the time you have more a role as employee and colleague, next to the role of student. It is possible that your new role requires other accommodations and support. Also in this situation you have to decide why, what and to whom you disclose your psychiatric disability in order to get the needed 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 stays your own decision to determine whether it is the right moment, the right situation, the right person and how much information you wish to tell.

5. How to tell?

To be open about your psychiatric disabilities is not a single matter. Often, in every new situation (**when**), or with every new person who you meet (**who**) you have to decide **whether** and **what** you tell about your psychiatric disabilities. Besides this it is also important **how** you tell it. To prepare yourself **how** to tell about your psychiatric disabilities, consider the following:

What can you do to prepare?

- know yourself and your psychiatric disability
- 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 discuss 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

If you tell

- 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 psychiatric disability
- describe how you overcome difficulties they may see as problems

- be prepared to deal with insensitive questions
- before the meeting, determine a good time and place, you both agree on, to discuss your psychiatric disability
- depending on your preference, you can visit staff at their student consulting times, phone them, e-mail them or write them a brief letter
- after lectures with other students listening, or in the cafeteria in a corridor, are less effective or appropriate times and places

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 yourself accepting 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 may be confidentiality, for example: 'If I disclose, then what will happen with this personal information?' 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. It is important to discuss what you and the other person mean by 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 an issue of duty of care, your safety or others (this is rarely the case), 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 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. Also use your intuition in this.

Discrimination

If you consider 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 organisation
- 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

Directions: 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. Identify benefits:	b. Identify risks:
c. Consider the balance:	

Disclosing your psychiatric disability

Worksheet 2

Directions: Think about your own situation and, in deciding how to tell, identify 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:	
b. Determine What you want to tell:	

Disclosing your psychiatric disability

Worksheet 3

Directions: Think about your own situation and, in deciding how to disclose your psychiatric disability, Identify Who to Tell.

- Remember to:
- a. Brainstorm relevant people
 - b. Select best choice

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

Disclosing your psychiatric disability

Worksheet 4

Directions: Think about your own situation and, in deciding how to disclose your psychiatric disability, Identify When to Tell.

- Remember to:
- a. Identify times
 - b. Choose best time

Identify When to Tell	
a. Identify times:	
b. Choose best time (and your reasons):	

Disclosing your psychiatric disability

Worksheet 5

Directions: Think about your own situation and, in deciding how to disclose your psychiatric disability, Formulate How to Tell.

- Remember to:
- a. Describe strengths
 - b. Explain disability

Formulate How to Tell	
a. Describe strengths:	
b. Explain disability:	

Disclosing your psychiatric disability

Checklist

Directions: After disclosing your psychiatric disability, rate your performance on each of the behaviors and related steps. Beside each behavior, write a description of what you said. Discuss your performance, if needed, with your Disability Specialist.

<i>Disclosing your psychiatric disability</i>	Yes	No	Partial	Comments
1. Choose Whether to Tell				
a. Identify benefits b. Identify risks c. Compare balance				
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 b. Choose best time				
5. Formulate How to Tell				
a. Describe strengths b. Explain disability				

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- Choosing your path. Disclosure: It's a Personal Decision. National Network of Regional Disability Liaison Officers & Disability Coordination Officers. University of Western Sydney and the University of Ballarat, 2003.
- Psychiatric Rehabilitation Practitioner Tools: Achieving Valued Roles. Skill: Disclosing Disability Information. BCPR Consulting, Inc., Center *for* Psychiatric Rehabilitation. Sargent College of Health and Rehabilitation Sciences, BU, 2004.

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, you'll find at the websites below:

The Netherlands

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

United States

<http://www.ssw.umich.edu/sed/>

An informative site about Supported Education of the University of Michigan / School of Social Work.

[Consumer Website for Handling Your Mental Illness at Work and School](#)

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/english/highered/index.html>

Information about the rights of students with psychiatric disabilities in Higher Education in Canada.

Australia

[The Learning Support Needs of Students With Psychiatric Disabilities](#)

Is an article of the University of Melbourne about the needs of students with psychiatric disabilities for education and support.

England

[Oxford Student Mental Health Network](#)

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

Colofon

The serie *Studying with support (in Dutch)* is a publication of the Research Department of Rehabilitation of the Hanze University Groningen, University for Applied Sciences. The serie is developed as part of the 'Studying with support' project, a collaboration project of the Research Department of Rehabilitation of the Hanze University Groningen, Cenzor, the Rehabilitation Department of GGz Groningen (a Mental Health Organization) and the Rehabilitation 92 Foundation in Rotterdam. The project was part of the national Impulse 2004 project of the Expertise Center Handicap + Studie and also funded in part by a grant from the Expertise Center Handicap + Studie in Utrecht, The Netherlands.

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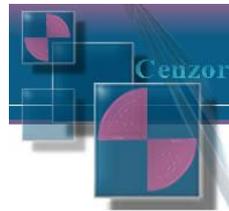
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