Factsheet 6: Disclosure of Disability - telling people about disability

Introduction

The term 'disclosure' is a commonly used term in relation to declaring a disability: in the literature as well as in general academic and clinical contexts. For this reason, we have chosen to include it in the title of this factsheet.

Some people, however, consider the term 'disclosure' to have significant negative connotations. They contend that it implies that disability is something to be ashamed of, and therefore to be kept hidden from others. They argue that it discourages a disabled person from discussing the implications of a disability and increases the already considerable pressure to 'pass' as 'normal'.

Given these characteristics, the term 'disclosure' definitely belongs to the Medical Model. In contrast, if you ask disabled students to 'tell' you about their impairment, this indicates that you regard disability as just another component of their individuality: such as age, gender or place of birth. If you invite students to 'tell' you about the practical significance of an impairment, they are far more likely to believe that your responses will not be negative. It is really important that you use language that reflects a positive attitude to difference so that communication between you and disabled students is ongoing. Where possible, therefore, we shall use the term 'tell' in this factsheet.

**Opportunities to tell others about a disability**

Whilst disabled people are not legally required to tell others about a disability, you should encourage them to do so. This enables reasonable adjustments to be implemented. Most people agree that the advantages outweigh the disadvantages.

**Example**

One student said: “I have never lied about my condition, I don’t see the point, it is part of me, it is part of my life and it is who I am”.

Many disabled people recognise these advantages in principle, but still find it hard to tell others about a disability and may choose not to. Because of this, it is really important for you to support and encourage students to tell you about the practical significance of an impairment whenever possible. The advantages should be emphasised.

Information about the process should be made available:

- on University websites
- in publicity materials
- in course materials so that applicants/students can think about their abilities in relation to defined competence standards
- during outreach work with local schools and colleges
- during the application process
- at open days, interviews and during Clearing
- during induction
- during assessments of study needs
- well in advance of assessment periods
- at academic reviews
• during personal tutorials
• prior to, and during, each practice placement

**How do you encourage your disabled applicants and students to tell you about a disability?**

**Take positive action**

Your institution's policies, practices and procedures should be positive, well publicised and familiar. Students should find it easy to tell you about a disability.

Positive strategies that you might use include:

- literature/website containing positive and non-stereotypical images of disability
- literature/website welcoming disabled applicants and providing detailed information on the range of facilities for disabled applicants and students
- an open, non-judgemental attitude
- encouragement of a frank and open dialogue in a safe and supportive environment
- reassurances about confidentiality and the processes involved in sharing appropriate information with relevant individuals
- reassurances that telling others about a disability or long-term health condition will not be evidence of ‘bad character’ or lead to disciplinary action
- flexible/adaptable institutional policies, practices and procedures
- good channels of communication between all staff including Practice Educators
- regular opportunities for students to make informed choices regarding their access requirements
- implementation and recording of effective support mechanisms
- inclusive environments
- accessible information
- inclusive teaching and learning opportunities
- provision of appropriate access technology and adaptations to the University network
- introducing new students to the University disabled students’ and staff network (if one exists)
Example

A speech and language therapy student who has mental health issues declared his disability on the UCAS form. He said that he had been reassured by the information provided about disability support on his University’s website and that all his contacts with Admissions and Disability support staff had been extremely positive. He had been worried about negative attitudes and stereotypical reactions but felt that it would have been irresponsible not to disclose. He received a great deal of support whilst on the programme but found the reception from practice educators rather variable. Once each placement began, however, he said that he felt, in general, that he was treated fairly.

Use appropriate language

It is important to use language that reflects a positive attitude towards disabled people. UCAS asks applicants to enter a code against a specific impairment. This method of recording the information is unfortunate because it reflects the Medical Model. Avoid language that focuses on a student's medical condition or that identifies the disabled person as responsible for 'the problem'.

Example

An applicant whose medical diagnosis is "bilateral congenital cataracts" attended an information exchange interview relating to his application to an AHP programme. Rather than asking what 'problems he would have' on the course or about his medical condition, the interviewers focussed on its practical significance in terms of the ways in which he managed both academic and other day-to-day activities. They were keen to find out about his current study strategies and what support he believed he would need when on the course. This gave him the opportunity to ask about the university's facilities for disabled students and what reasonable adjustments would be made to meet his particular requirements on the course.

Emphasise the services available, not disability or medical conditions e.g.

- Process/procedure for accessing support
- Support for students to access text based resources
- Facilities for students who use computers with assistive technology
- Modification of examinations and assignments
- Facilities available for disabled students in the library/learning resource centre
Availability of note-takers
Loan of DVDs with audio description and/or subtitles
Loan of anatomy and physiology models or other appropriate equipment (if available)

Always be welcoming and friendly.

Confidentiality

The university confidentiality policy should be well publicised. Reassure students that information will remain confidential. Warn them, however, that if they insist on total confidentiality, but require reasonable adjustments, implementation may be difficult.

Example

A student who has dyslexia told his personal tutor but insisted that this information could not be passed on to other members of staff. A lecturer issued handouts from which the students were required to work during a practical class. The student complained to his personal tutor that he did not receive these before the session or in an accessible format. He said that he was unable to read the text and therefore could not participate fully in the class. He was told that his insistence on confidentiality made it impossible for the personal tutor to ask the lecturer to provide him with the handouts in advance.

Because this student wanted to 'pass' as non-disabled, his support needs were not met. Had he felt able to tell others about his disability, the reasonable adjustment would have been implemented. If teaching practices had been inclusive, however, all students would have received handouts in advance, benefiting everyone.
Issues around telling others about a disability

There are likely to be occasions when you are unaware - at least initially - that a student is attempting to avoid telling you about a disability.

Example

Because of having bipolar affective disorder (a recurring form of depression) a student requested to work only 4 days each week on her 5 week practice placement. The reason that she gave to her Practice Educator for this, however, was related to her having a long journey to work.

The request was denied because:

1. It was considered to be detrimental to her overall placement experience;
2. It was inconsistent with usual practice and
3. It left her no flexibility in placement hours in case of illness or other absence.

Had this student felt more able to talk about her disability and not insisted on confidentiality, some modification of her placement working hours would have been regarded as a reasonable adjustment.

Who can be told about a student's disability?

Inform students that, with their permission, information can be shared with relevant staff regarding reasonable adjustments. Reassure them that the details of impairments do not need to be included.

You should:

- Talk to the students to see with which staff they are comfortable for the information to be shared
- Ask students what information can be passed on and in how much detail
- Ask the student to sign the agreement
- Counter sign and date the agreement
- Retain a copy in the student's file

Much of this may be carried out by the Learning Support/Disability Officer
Example

A member of academic staff said: “I think it is really important that students are encouraged to be open about their issues but more importantly that they can articulate their strategies for dealing with them. We discuss this with students and they complete a form at the start of the programme which identifies clearly who will be told about issues and who will tell them and what will be disclosed”.

Telling others about a disability: some barriers

Labelling

A person can be classified as disabled under the legislation but may not identify with this classification.

Example

One student said: “If I’m asked ‘are you disabled?’ I tend to say ‘no’ because I really don’t consider myself disabled”

Some see this as a negative ‘label’.

Example

A student said: “the word itself suggests you’re incapable, the whole stigma that goes with it says you can’t function, you can’t do something, it’s negative in itself”

What students think/are affected by

Applicants who have unseen impairments may choose not to talk about them because they believe that:

- They won’t be offered a place on the programme
- They will be treated differently from non-disabled students (Rose 2006)

The reasons why students choose not to tell you about a disability are complex, associated with cultural, social and psychological factors including:
Pressure to be ‘normal’
Pressure to conform socially
Fear/previous experience of discrimination, bullying, harassment, victimisation, isolation, rejection
Fear/previous experience of triggering stereotypical reactions causing stigma and prejudice
Denial of impairment
Unwillingness to identify with other disabled people
Embarrassment when associated with particular images/ stereotypes of disability
A need to be accepted, especially by peer group
Aesthetic considerations (refusal to wear a hearing aid, glasses with ‘thick’ or coloured/tinted lenses or to use a walking stick)

Example

A Deaf applicant did not tell anyone about her disability as she had Deaf friends who had been refused places on degree programmes. Not disclosing meant that, once enrolled on the programme, she had to conceal the fact that she was a lip reader. This was very stressful.

Her first practice placement was really difficult and so, part way through, she decided to tell her Practice Educator about her disability. Her Practice Educator’s response was: “I don’t see how I can pass you because you are deaf” (NB This is Direct Discrimination). The student became very depressed.

The academic staff were very supportive but didn’t really know the best way to help. Due to high stress levels, she decided to take a break from the programme.

During this time she made contact with the university’s Disability Unit and was able to organise effective support which meant she could return and successfully complete the degree. Because of this situation the academic team decided to undertake disability awareness training. They improved communication links with their Practice Educators regarding support for disabled students and passed on ideas about helpful strategies during their regular update sessions.
The choice not to tell others about a disability

If students choose not to tell you about a disability, it is important for them to understand that they must accept the responsibility for not doing so. Support might not be implemented and this could affect their educational achievement.

Students have the right to tell you about a disability at any time but universities have a duty to anticipate the potential requirements of all disabled users. This creates a more inclusive environment and avoids delays in implementing more specific support.

Example

A student was happy to tell staff that she has an ongoing back problem as she felt that it “didn’t carry any embarrassment factor”. She was not willing, however, to tell them that she is a mental health services user because “there’s a stigma to it and it’s not something you talk about. I don’t think I would get the understanding”

If there had been a more open and inclusive environment in her institution, with publicity about available support including positive case studies regarding mental health issues, she may have been more willing to tell staff about her condition.

People who have mental health issues often fear stigmatisation and prejudice. Temporary states of distress (e.g. bereavement) should not be recorded as a ‘permanent condition’ because of the negative and ongoing consequences. Students in this situation should be dealt with sympathetically as even temporary distress can affect performance.

Fluctuating conditions

For people who have fluctuating conditions (e.g. depression, multiple sclerosis) telling anyone about them can be difficult. The effects of such conditions may be triggered by a crisis or by entering a more stressful environment such as a practice based placement. Some, however, still choose not to tell staff. This can lead to lack of support and/or misconceptions about reasons for poor performance or underachievement. Again, if you have an open and non-judgemental approach and provide numerous opportunities for students to tell you about a disability, this can help to avoid this situation.
Language/terminology

Students often find it hard to talk about ‘disability’ or their ‘condition’. Dealing with the impact of disability can be very challenging for students and this can be exacerbated by taking a medicalised approach which focuses on their ‘symptoms/problems’ or what they might be unable to do. This may be particularly the case if they have only recently received a diagnosis. It is much more supportive if you can discuss the implications or impact on their ability to manage the learning situation. You will generally find that they respond more positively to a session where you discuss their learning requirements, providing encouragement and support.

Example

A student identified herself as being extremely stressed during practical examinations, especially when timetabled towards the end of the day. The module leader discussed this with her and asked what she felt might be a good strategy for dealing with this situation. She said it would be really helpful if she could take the exam in the first half of the morning as this would reduce her stress levels and help her to perform better. This was considered to be a reasonable request and was agreed.

Some students will come up with ideas for personal strategies; others may need you to provide some suggestions or guidance.

After you have been told about a student's disability

When a student has told one member of staff about a disability and has given consent for sharing of information, the whole institution is legally considered to know. If students do not consent, you must emphasise that this will have an impact on what they can legally expect of the institution. Once the institution knows about a student’s disability, there should be an agreed process for informing the relevant personnel about reasonable adjustments: the student is not responsible for communicating this information. It is important that all staff approach this situation sensitively.

Example

One student said: “I told my Personal tutor about my disability who then told me that because she knew, all the staff on my programme and all my practice educators had to know about it. I was really unhappy about this....I had only just been diagnosed.....it was very personal and I wasn’t ready for it. I felt like leaving”
The Data Protection Act (1998) prohibits staff from disclosing information about students’ disabilities (considered to be sensitive, personal data) without their consent. Students who have given permission should not be expected to repeat this process again. You need to respect students’ privacy rights but you should give them the option for information to be shared with relevant staff if they wish (Stanley et al 2007).

Practice based placements

The practice based setting can highlight different issues from those which students meet in their academic studies. Students often go to new environments on every placement and if reasonable adjustments are to be implemented successfully, the Practice Educator needs to know about the practical implications of a student's disability. In some cases, the student gives permission for the university to pass on agreed information. It is also helpful if you can encourage and support the student to talk to the educator in advance of the placement.

Practice Educators have said that they like to talk to the student in advance because:
1. It helps them to prepare any reasonable adjustments and to allocate work appropriately
2. It helps them to understand the student’s strategies and raises their awareness of the ways they can support disabled students more effectively
3. It saves time at the beginning of the placement
4. It helps them to enable the student to get the maximum benefit from the placement

Practice Educators want students to have this open and frank discussion with them. For many of the reasons discussed earlier, however, this is not necessarily an easy option for students. They must be provided with well publicised and supportive opportunities for this discussion and must be dealt with sensitively.

Telling people about a disability: managing risk

There may be situations in which a student has told academic staff about an impairment but does not want this information to be passed on to Practice Educators. This is the student’s right but carries with it a responsibility to have his/her personal strategies in place in order to perform effectively on placement. On rare occasions, depending on the stability of the student’s condition, you may need to make a judgement about possible risks that could present on placement.
Example

A student who has recently been diagnosed as having diabetes is still in the process of learning to control the condition. He had to leave two practical classes in order to have something to eat as he was observed to be behaving unusually. He was about to go onto a practice placement and was reluctant to tell his educator about the situation.

Academic staff were concerned that a similar incident may occur when he was treating patients and recognised the need to discuss this with him.

Possible outcomes:
1. The student felt very uncomfortable about telling the practice educator about his diabetes and refused consent. As a result academic staff decided, on health and safety grounds, to postpone his placement until he was more familiar and confident with his diabetic control regimen.

2. The student recognised that there could be a potential risk and requested that his personal tutor initiated a discussion with the practice educator to implement reasonable adjustments. It was agreed that additional short breaks would be incorporated into his timetable, that he would be working on the wards with another member of staff in the area and staff were informed about how to recognise relevant signs of when he may need to take action.

3. As for scenario 2 but in this case the student took the responsibility of discussing and negotiating the reasonable adjustments himself.

Web links


References

Rose C (2006) Do you have a disability – yes or no? Or is there a better way of asking? Guidance on disability disclosure and respecting confidentiality. Learning and Skills Development Agency, London


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Acknowledgment

The Allied Health Professions Support Service (AHPSS) was launched in 1991 in response to the closure of the Royal National Institute for Blind People's (RNIB) School of Physiotherapy which catered exclusively for visually impaired students. AHPSS’s remit was to provide support to disabled allied health profession students in mainstream higher education in the UK. It also offered information, advice and specialised disability awareness training to academic and practice-based staff.

In 2002, AHPSS staff were invited by the Chartered Society of Physiotherapy (CSP) to join a team of specialists to produce a training manual specifically designed to provide guidance for practice based staff in supporting disabled students on practice based placements. The document: "Supporting Physiotherapy Students on Clinical Placement", was published in 2004 and received very positive feedback from all stakeholders.

By 2007, it was evident that the document needed updating in response to UK legislative and technological changes and the increasing use of online information. Following discussions with CSP staff, it was agreed that the AHPSS team (Jane Owen Hutchinson, AHPSS Manager and Karen Atkinson, Senior Lecturer and Manager of the RNIB Resource Centre at the University of East London), would take on this project.

Between 2007 and 2010, considerable time was spent in obtaining feedback from a wide range of stakeholders regarding the content and format of the future document. Whist it was unanimously agreed that it should be available in both hard copy and electronically, all staff identified the importance of being able to access some of the specific guidance on disability management from the AHPSS website.

"Into Physiotherapy" was published by the CSP and RNIB in 2010. Thirteen related information sheets were subsequently uploaded onto the AHPSS website (between 2010 and 2013), at which point the AHPSS was decommissioned by NHS London. As a result of the positive feedback these fact sheets received and requests from a number of organisations, Jane Owen Hutchinson and Karen Atkinson have given permission for these materials to continue to be available online.