Guidance for colleges and other post-16 education providers on implementing the Disability Discrimination Act learning and skills development agency

# Do you have a disability – yes or no?

or is there a better way of asking?

Guidance on disability disclosure and respecting confidentiality

**Christine Rose** 

Guidance for colleges and adult education providers on encouraging disclosure



# Do you have a disability – yes or no?

# or is there a better way of asking?

Guidance on disability disclosure and respecting confidentiality

**Christine Rose** 

Published by the Learning and Skills Development Agency

www.LSDA.org.uk

LSDA is committed to providing publications that are accessible to all. To request additional copies of this publication or a different format, please contact:

Information Services Learning and Skills Development Agency Regent Arcade House 19–25 Argyll Street London W1F 7LS. Tel 020 7297 9144 Fax 020 7297 9242 enquiries@LSDA.org.uk

Registered with the Charity Commissioners

Copyeditor: Nick Sweeney Designer: Joel Quartey Printer: Blackmore Ltd, Shaftesbury, Dorset

052243SP/01/06/3000

ISBN 184572349X

© Learning and Skills Development Agency 2006

You are welcome to copy this publication for internal use within your organisation. Otherwise, no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, electrical, chemical, optical, photocopying, recording or otherwise, without prior written permission of the copyright owner.

#### **Further information**

For further information about the Learning and Skills Council visit www.LSC.gov.uk

This publication results from the Learning and Skills Development Agency's strategic programme of research and development funded by the Learning and Skills Council, the organisation that exists to make England better skilled and more competitive.

# Contents

1	Introduction	1
2	The context	3
	The requirements of legislation	3
	The language of 'disability'	4
	The terminology debate	5
	Cultural use of language	6
3	Communicating support options and availability	7
4	Disclosure during admissions	11
	Questions on application and enrolment forms	11
	Statements on enrolment and other forms	20
	Interview processes	22
	Enrolment processes	23
5	Ongoing opportunities for disclosure	25
	Tutorials and induction	26
	Examinations	27
	Trips	27
	Work experience	28
	Avoiding intrusion	29
	Ongoing opportunities for part-time courses	29
	Appropriate approaches	30
	Disclosure via a third party	31
6	Respecting confidentiality	33
	Consent forms	33
	Other pitfalls to avoid	37 41
	Meaningful consent Respecting confidentiality	41
	Disclaimer statements	42
7		
'	Developing disclosure and confidentiality procedures	45 45
	Stage 1 Stage 2	40
	Stage 3	47
	Stage 4	48
	Stage 5	49
	Stage 6	49
	Pitfalls to avoid when producing policies and procedures	49
8	Embedding new procedures in practice	53
	Senior/executive management support	53
	Staff training and development	54
	Monitoring and evaluation of procedures	55

9	Conclusions	57
	References	58
Appendix A	Suggested training plan and case studies	59
Appendix B	Skeleton disclosure and confidentiality policy	78

#### **Acknowledgements**

This report is one of a series of resources from the project, The Disability Discrimination Act: taking the work forward 2003–05, managed by the Learning and Skills Development Agency (LSDA) in partnership with NIACE and Skill, supported by the Disability Rights Commission and funded by the Learning and Skills Council. More than 100 organisations have been involved in a total of twenty projects related to DDA implementation in further education, adult community learning and work-based learning.

I would like to offer thanks to the main writer Dr Christine Rose for all her efforts in generating this report from the projects. I am also extremely grateful to the research sites who contributed to the project and to the many people who offered comments and suggestions which have helped to shape this publication.

I hope you will find this a valuable resource for helping you to respond to the DDA.

Sally Faraday Research Manager Learning and Skills Development Agency

# 1 Introduction

Many providers are keen to implement the requirements of the Disability Discrimination Act (DDA), seeing this as an opportunity to further improve the experience of disabled learners. However, the DDA Part 4 raises many issues about the ways in which education providers encourage a learner to disclose an impairment in order to make adjustments, the procedures organisations have in place for passing on relevant information, and the ways in which they can respect a learner's desire for confidentiality.

National guidance 'Disclosure, passing on of information and confidentiality; guidance for post-16 education providers on implementing the DDA Part 4' was published in October 2003 and subsequently released to all post-16 education providers via local LSCs<sup>1</sup>. The purpose of this report is to discuss how the sector has responded to this national guidance, the challenges that providers face in implementing the requirements of legislation and to provide some examples of practice in the sector. This report builds on, rather than repeats, the information contained in the national guidance, so you may find it useful to read this report in conjunction with the guidance document.

Section 2 of this report provides an overview of the context of disclosure, summarising the requirements of the Disability Discrimination Act (DDA) and the Data Protection Act (DPA). This section also explores the language of 'disability' and the medical and social models of disability. The remaining sections provide practical examples of how the sector has responded to the legal requirements of the DDA and the DPA. Section 3 explores how to encourage disclosure by effectively communicating support options and availability. Sections 4 and 5 examine how to encourage disclosure. Section 6 discusses confidentiality and the mechanisms for obtaining consent.

<sup>1</sup> Maudslay L and Rose C (2003), *Disclosure, passing on of information and confidentiality*. London: LSC. Available via www.lsc.gov.uk, accessed March 2004

Section 7 looks at the process of producing disclosure and confidentiality policies and procedures, while Section 8 considers aspects that influence the successful embedding of these in practice. Appendix A provides some exemplar staff development materials that providers may find useful for training sessions within their own organisations. Appendix B contains a skeleton disclosure and confidentiality policy adapted from the national guidance mentioned above.

Questions are posed throughout for you to consider as you continue to work towards implementing the requirements of legislation and improving practice.

A number of examples and quotes in this report are from providers involved in national action research projects run by the Learning and Skills Development Agency (LSDA), in partnership with Skill and NIACE. These are referred to as project sites in this report<sup>2</sup>. Other examples and quotes are from staff and learners in further education (FE) colleges, sixth form colleges and adult and community education services who have been willing to share their practice, progress, success and difficulties in encouraging disclosure, passing on information and respecting confidentiality. The contributions of all are gratefully acknowledged.

# 2 The context

## The requirements of legislation

In September 2002, the Disability Discrimination Act Part 4 (DDA Part 4) introduced new legal rights for the education of disabled people. The definition of a disabled person is quite broad and can include people with a physical or sensory impairment, as well as 'unseen' impairments such as dyslexia, mental health difficulties and epilepsy. It is likely that up to one in six learners are covered by this definition. This estimate is based on adults of working age who fall within the definition of the DDA, and is taken from a survey commissioned by the Department for Work and Pensions, March 2004.

The Code of Practice to the DDA Part 4 makes clear that once one member of an organisation knows about a learner's impairment and providing the learner is happy for this information to be shared, the whole organisation is deemed to know. The reasoning behind this is that organisations should have effective channels of communication so that information is passed on to appropriate staff. It should not be left to the learner to have to go to every relevant member of staff, repeatedly informing them of their support requirements.

Under the Data Protection Act 1998, medical information and information about impairments are classified as 'sensitive'. This means that following disclosure, information cannot be passed on to anyone else internally or externally without the learner's explicit informed consent. Under the DDA Part 4 a learner has the right to request that the existence or nature of his or her impairment be treated as confidential; this reinforces the requirements of the Data Protection Act. It is important to appreciate that consent cannot be inferred by silence. If a learner doesn't ask for confidentiality, this should not be taken to mean that they have given consent for information to be passed to others. Under the DDA Part 4, providers are expected to be proactive in encouraging people to disclose. This involves providing appropriate and effective opportunities for disclosure, not just during the admissions process but also throughout the course, for example before a trip or a work placement. Effectively encouraging disclosure also involves providing an atmosphere and culture where disabled learners are valued, information is dealt with sensitively, and confidentiality is respected.

# The language of 'disability'

The language that people use can reflect what they think and can influence how they deal with situations. A person who thinks and behaves as if a problem is located with an individual, may take a different approach to someone who see the problem of 'disability' located with the attitudes, systems and practices that can create disabling barriers. This is in line with two contrasting models of disability: the medical model and the social model.

The medical model of disability reinforces the idea that the problems people face are a direct result of their own health or impairment. This model takes a narrow, labelling approach that can perpetuate stereotypes and create a cycle of dependency and exclusion that is often difficult to break.

The social model of disability, in contrast, refutes the medical perspective above, and shifts the focus from what is 'wrong' with the disabled person to what is wrong with attitudes, systems and practices, as it is these that often create disabling barriers and prevent participation by disabled people. The social model of disability promotes the right of a disabled person to belong, to be valued, to determine choice and to make decisions. Education professionals work alongside the person in order to identify the organisational and attitudinal barriers. They then develop solutions, make adjustments and provide support to overcome these barriers. The emphasis is taken away from the disabled person and is placed firmly with the provider.

## The terminology debate

The question of disability terminology is the subject of much debate among disabled people. The language we use is important because words reflect our attitudes and beliefs.

Some disabled people prefer to be called 'people with disabilities' because they want to be regarded as people first. Others prefer the term 'disabled people', arguing that in the social model of disability, the experiences of impairment and disability are separate. They would define these terms in the following way:

- Impairment is the physical, mental or sensory characteristic, feature or attribute that affects the function of an individual's mind or body.
- Disability is the loss or limitation of opportunities to take part in society on an equal level due to social, attitudinal and environmental barriers such as inaccessible buildings, inflexible organisational procedures and patronising or negative attitudes.

People who prefer this terminology would argue that the term 'people with disabilities' suggests that the disability 'belongs' to the disabled person, rather than more accurately belonging to a society that disables. However, some disabled people dislike the term 'impairment'.

While everyone would agree that barriers are created by the society in which we live, there is no complete agreement among disabled people as to what is appropriate terminology, and we recognise that this is a sensitive and complex issue. We have tried to use the term 'impairment' where possible within this report and tried to confine the use of the term 'disability' to refer to the organisational, environmental or attitudinal barriers that disabled people experience in education. However, we have not always been able to do so, for example when looking at questions on enrolment forms and discussing disability statements. We have continued to use 'disabled learners' and 'learners with disabilities and learning difficulties' interchangeably as the roots of both these expressions lie in legislation and are the current terms used and understood in the education sector.

In addition, there are issues about the use of the word 'support', as this is open to misunderstanding and potential misuse in reinforcing a medical model approach. However, in the context of education, 'support' has broader connotations and can be taken to mean the services, facilities, equipment and resources available to all learners, such as tutorial 'support'. In this document, 'support' should be seen in this context and taken to mean the organisation's responsibility to make adjustments to meet disabled people's legal rights to education and inclusion

## Cultural use of language

Different cultures may have different concepts of impairment and may not readily identify with the words commonly used to encourage disclosure. In some cultures, for example, there is no obvious translation of the term 'learning difficulties'. Some of the words used to define impairment, when translated literally, can often anger people from disabled groups in the UK, who have fought hard to establish the use of words which do not have derogatory connotations. However, this needs to be understood in the context of a society in which these are the recognised terms. A mother of a son with learning difficulties at one of the project sites, for example, made the point that although she did not like these words, they were the only words available to her to describe her son's impairment in her own language.

The language we use, the approach we take and the particular model of disability we adopt can influence all the ways in which we encourage disclosure. For example, the ways we communicate the support available, the questions we ask on enrolment forms, and the ways in which we provide ongoing opportunities for disclosure. The following sections of this report provide some practical examples of how we can more effectively encourage disclosure by taking account of these factors.

# 3 Communicating support options and availability

The organisation's prospectus, website and other marketing materials provide an opportunity to give clear information on the support available for disabled learners. Effectively communicating the options, availability of support and the benefits of disclosure plays an important part in encouraging learners to disclose.

Many providers use their prospectus as a key marketing and communication tool. It is helpful if the information on support is close to the front and includes contact details of staff that can provide further information, and signposts the organisation's disability statement. However, information in a prospectus is often focused on the support for learners with a physical or sensory impairment or a specific learning difficulty such as dyslexia. Fewer organisations have information that explains how they value and support all disabled learners, including, for example, learners with mental health difficulties and learners with Asperger's Syndrome.

One college has given their disability statement the title 'Support for You', recognising that learners may have a narrow perception of what is meant by the term 'disability'. The statement is in booklet form and includes learner photos and success stories. Another college initiated a joint project with disabled learners and the media department to produce a new, learner friendly disability statement, written for disabled learners by disabled learners. All colleges should have an up-to-date statement that summarises the support available for disabled learners. Faraday and Maudslay (2000) evaluated college disability statements and made a number of suggestions on the ways in which such information could be improved. You might find this useful.

Many colleges have summarised their disability statement within information leaflets that welcome disabled people, promote support and again provide contact details and how further information can be obtained. However, it is important that such leaflets are widely displayed at key points such as reception, student services and the learning resource centre, and are available in accessible formats. One project site noted: Some students expressed surprise that some facilities had existed that they had not been aware of, or thought they had no entitlement to use... it became clear that facilities need to be explicitly advertised around the building. Although these facilities had been listed in information leaflets to the students they needed to have a cultural presence in the students' environment.

One project site has drafted a letter that will be sent to all who enrol, welcoming them to the college. This letter explains the purpose of additional support and how it can be accessed, and introduces the additional support team. They have also produced a statement about support, with key contact names and numbers, on the back of each learner's membership card.

One local education authority (LEA) contracts out adult and community learning (ACL) provision to a considerable number of centres, and has produced a leaflet to help ensure that disabled learners and potential learners are aware of the options and availability of support. The leaflets summarise the support available, the accessibility of centres, and provide named contacts and telephone numbers for further information. Centre managers are responsible for displaying the leaflets and ensuring that tutors discuss support options with learners at the start of the course.

Some colleges include statements on the options, availability and benefits of support within student handbooks and diaries. One college has a leaflet in the shape of a mobile phone with a text message for students encouraging them to access support.

One project site is conscious that the general lack of awareness among staff and learners about how to support learners with mental health difficulties is having an impact on disclosure processes. For example:

(A learner) was a first year AS student who had excellent GCSE results and was clearly very academically able... She disclosed that she had bipolar disorder and that she suffered from acute depressions that left her unable to get herself motivated. When the teacher asked why she had not told the staff of this condition before she asked 'what's the point, what can they do?' She was unwilling to have this information passed on to tutors even though she was likely to be thrown out of college for what appeared to be a lack of interest in her studies.

This site is developing a mental health policy and has planned staff training on supporting learners with mental health difficulties. This site is also producing leaflets for learners with mental health difficulties that outline the range of support available and the benefits of disclosure.

- Do your marketing materials and information leaflets describe the support available for disabled learners? Do these include traditionally under-represented groups such as learners with mental health difficulties and with Asperger's Syndrome? Are they widely available to learners and potential learners? Are they available in accessible formats?
- Do you target publicity materials through networks that involve disabled people, for example local mental health trusts?
- Are your marketing and communication strategies effective in explaining the options, availability and benefits of support to all learners and potential learners? Have you consulted with disabled learners on how these might be improved?

Promoting visible signs that diversity and disabled people are valued will influence disclosure. One organisation has an annual event where a week is devoted to celebrating the achievements of disabled people and exploring aspects of disability discrimination. Another has a plasma screen in the canteen and posters displayed around the buildings that promote and advertise support. One college has included a module in the tutorial curriculum that explores the discrimination that disabled people can sometimes face, including attitudes of other learners. One organisation ensures that disabled learners are represented on a wall display of learner success stories.

One project site made the following suggestion, regarding the location and accommodation of learning support:

It can be busy, welcoming and noisy. It could have music, coffee machines, carpets, comfortable chairs and working areas. It could have a buzz! It should have private rooms off it for one-to-one support and interviews. It should have private and confidential office space for storage. PCs should be included, loaded with specialist software. Students will be aware that other students are in the same situation as themselves and that it is nothing to be ashamed of. We need to be very open and upfront about the important services that we provide. If we don't hide ourselves away, maybe the students won't either One sixth form college has an annual open day with signs on display as people walk into the building, showing the support available for disabled learners. Leaflets are handed out that help advertise and promote the support that can be provided, additional support staff are available to answer questions, and opportunities for confidential discussions are advertised. Learners, including disabled learners, conduct guided tours.

# Do you have visible signs that diversity and disabled people are valued?

How might these be improved?

# 4 Disclosure during admissions 11

Effectively encouraging disclosure during the admissions process is fundamental to ensuring that learners have appropriate adjustments in place as soon as they start their course.

# **Questions on application and enrolment forms**

The use of language plays an important part in encouraging disclosure, particularly on application, enrolment and other forms that learners are asked to complete. Some organisations duplicate a question requesting information about a learner's impairment on both an application and an enrolment form, while others use different questions. The following are common examples of questions that are unhelpful as they take a labelling, medical model approach, focusing on what is 'wrong' with the learner, rather than focusing on the adjustments that the organisation can make to meet the legal rights of disabled learners.

# **Example 1**

Do you have a disability?

# Example 2

Do you have a disability as defined under Yes No the Disability Discrimination Act?

# Example 3

Do you have a disability or learning difficulty? Please tick the relevant box

No known disability	00 🗆	Mental health difficulty	06 🗆
Dyslexia	01 🗌	'Unseen' disability eg asthma, diabetes, epilepsy	07 🗌
Blind/partially sighted	02 🗌	Multiple disabilities	08 🗆
Deaf/hearing impairment	03 🗌	Disability other than listed	09 🗌
Wheelchair user/mobility problem	04 🗌	Disabled	99 🗌
Personal support need	05 🗆		

# Example 4

Do you have a disability or le	🗆 Yes 🗖 No				
If yes, please tick the relevant box					
Visual	Other physical	Hearing			
Profound and complex	Mental health	Disability affecting mobility			
Dyscalculia	Wheelchair user	Emotional / behavioural			
Other (please state)					
Moderate	Severe	Multiple			

# Example 5

Do you have any special needs or additional	Yes	🗌 No
learning support requirements?		

Please collect a Disability Statement from reception

# Example 6

Are you disabled?	Yes	🗆 No
Do you wish to discuss your needs with an	Yes	🗌 No
appropriate member of staff?		

12

# Example 7

Do you have a disability or learning difficulty that will affect your learning?			Yes	🗆 No	
Example 8					
Are you registered disabled	1?		Yes	No	
Example 9 – formatted from original form					
Do you consider yourself to have any of the following disabilities or learning difficulties?				No	
If YES, please tick one or m	ore of the following	boxes			
Visual impairment 🛛 01	Mental ill health	07	Severe learning difficulty	02	
Hearing impairment 🔲 02	Temporary disability after illness	08	Dyslexia	□ 10	
Disability affecting 03 mobility/wheelchair User	Profound / complex disabilities	09	Dyscalculia	□ 11	
Other physical 04 disability	Multiple disabilities	90	Other specific learning difficulty	19	
Emotional 🛛 05 behavioural disability	Moderate learning difficulty	01	Multiple learning difficulties	90	
Other (please specify)					

# Example 10

Do you have a disability or learning difficulty that may affect your learning while at the College?

If yes, please provide further information

In addition to encouraging the medical model approach, there are a number of further difficulties with these questions, including the following:

- Learners may have a rather narrow perception of what is meant by 'disability', particularly if examples are not provided, and may not consider that they have a 'disability' if they have, for example, dyslexia, epilepsy or a mental health difficulty.
- There is a questionable breach of the Data Protection Act (DPA) if a learner discloses an impairment such as a mental health difficulty. Enrolment forms usually have a Data Protection Act statement at the end, and a place for a learner's signature, but these do not provide the meaningful consent that is required under the DPA for sensitive information. This is discussed further in Section 6.
- The use of the term 'special needs' is unhelpful and should be avoided. It is the name for the process of assessing and statementing children in schools in England and Wales in order to provide additional support and equipment and is not applicable in the post-16 education sector. Disabled people often do not like this term as it can imply that they are to be pitied or that they are somehow more heroic or courageous than others, reinforcing the medical model of disability. There are conflicting opinions regarding terminology and schools, parents and learners may use this term but it is helpful if post-16 education providers avoid this term where possible.
- Applicants may perceive that these questions are actually questions to help the organisation to determine whether or not to offer a place. This perception can be reinforced by other questions on the form. For example, one college has an enrolment form that asks the following two questions together:

Do you have a disability?	Yes	🗌 No
Do you have a criminal conviction?	Yes	🗌 No

No one had thought through the implications of putting these two questions together.

Many learners will not be 'registered' disabled yet are entitled to reasonable adjustments under the DDA.

- There is no mention of the benefits of disclosure. The reason that people are asked to disclose is so that the organisation becomes aware of a learner's requirements and puts adjustments in place to provide an equitable service.
- There is no mention of what will happen as a result of disclosure.

Before exploring some examples of questions that try to avoid these difficulties, it is useful to consider the views of disabled learners. A number of project sites conducted a range of learner consultations and found that learners generally have a very narrow perception of what is meant by the word 'disability'. Learners also did not like a 'tick box approach' to identifying their impairment.

People can get labelled at an early age and it can have an effect on you I think. If I had to tick one of those things in that box, I would see it as a major put down on myself... you shouldn't have to label yourself... it's like putting a stamp on my own head saying 'Look at me I'm disabled'.

I have dyslexia but I don't have a disability.

One project site commented:

Students found the box 'prescriptive', 'in your face' and discriminating... Some students were concerned that they wouldn't know which box to tick... Other students found the categories too sweeping or broad... In response to the question 'can you imagine circumstances in which people might not come forward' one student noted the 'mentally ill'. That again is so vast an area. To tick a box to say mentally ill that can be anything from mild depression through to schizophrenia... Students often don't want to put themselves into a box. Other students, particularly those with dyslexia, dyspraxia, and dyscalculia do not like to be identified as disabled or as having a learning difficulty.

There is a very real fear that students ticking boxes, and approaching learning support will be labelled in such a way and made to feel different. If questions on application and enrolment forms focus instead on the support that can be provided and the benefits of disclosure, then learners are much more likely to disclose. There are likely to be fewer misunderstandings or anxieties about why an organisation is asking these questions. The following are some examples that try to take this approach.

# Example 11

Do you have a disability or learning difficulty?

We want you to get the best from your course. How would you wish to let us know how we can best support you?

By talking confidentially to a member of staff at interview	
By talking confidentiality to a member of staff by telephone	
In writing (please attach)	
Through someone else such as an advocate, parent or carer who will accompany you to your interview	

This is more positive than previous examples, in that it focuses on the responsibilities of the organisation. Perhaps the title could be improved by asking the question 'Are you a disabled person?' and by giving some examples of impairments.

# Example 12

We are committed to meeting the needs of people with learning difficulties or disabilities, so please let us know if you require additional support. We offer a range of support services for students.

If you tick either of the boxes below, we will send you a Disability Support questionnaire to help us in establishing your support need.

I have a disability and will need support.	
I have dyslexia and would like support.	

Again, the focus is much better, although perhaps it could be improved by stating 'we are committed to meeting the requirements of disabled people' and again giving some examples. Another improvement might be to replace 'I have a disability and will need support' with 'I am a disabled person and would like to discuss the support available', and make a similar alteration to the box below regarding dyslexia.

# Example 13

#### **Student Support**

The college provides a wide range of additional support. Please let us know if you have a disability such as visual impairment, mental health difficulty, a medical condition such as epilepsy, ME, or if you are hard of hearing, have dyslexia or you are a wheelchair user, for example. We will contact you in confidence to discuss possible support arrangements.

I have a disability / learning difficulty and would like to be contacted.

This question is helpful as it starts by stating the responsibility of the organisation, but perhaps it could be improved by replacing ' I have a disability/learning difficulty and would like to be contacted' with 'I am interested in the support available and would like to be contacted'. It might also be improved by replacing the word 'disability' with 'impairment,' although some people reading the question may not be aware of the difference between the two words in the social model of disability.

Although we have seen that there is still room for improvement in examples 11-13, they all try to avoid a medical model approach and focus instead on the organisation's responsibility to meet the requirements of disabled people. None breach the Data Protection Act by passing on specific information about an impairment without explicit consent. One college was concerned about the number of late disclosures, ie disclosures after the admissions process. Changing the wording on application and enrolment forms doubled the number of learners disclosing during the admissions process.

However, there are implications for MIS (management information systems) if questions are altered, as many have mechanisms that use the information on the enrolment form to populate the learner ILR (Individualised Learner Record) field for impairment on the organisation's data base. Alternative processes should therefore be explored. For example, one college has introduced a process whereby a member of staff from the additional support department interviews any applicant or learner who discloses. Following the interview, the learner is asked to give consent to pass information on to relevant staff, including MIS. The revised process is included in a new disclosure procedure. One of the additional benefits of this revision is that MIS now captures impairment data about learners who disclose after enrolment. These issues are further discussed in Sections 6 and 7.

ACL providers have not been required to submit data to the LSC on numbers of disabled learners in the same way as colleges. Not all ACL providers ask, therefore, if a learner has any support requirements at enrolment. However, a question on an enrolment form can provide an important opportunity to encourage disclosure. One organisation has modified its enrolment form by inserting the question below, as part of a new disclosure procedure.

## Example 14

#### **Disability/Learning difficulty**

We offer a range of additional support facilities. Please let us know if you have a disability such as wheelchair user, partially sighted, Deaf or hard of hearing, mental health difficulty, or a medical condition such as epilepsy. Please also let us know if you have dyslexia.

- □ I would like a member of staff to contact me to discuss my requirement, in confidence.
- □ I would like further information about the support available. Please send me a leaflet.

Again, this might be improved by a different heading, such as the suggested heading in example 11.

Another ACL provider revised its enrolment form and now asks the following question:

# Example 15

#### Meeting your support requirements

Do you have:

- A disability, for example visual impairment, hard of hearing, mental health difficulty, mobility difficulty?
- A learning difficulty, for example dyslexia?

If so, please tick this box 🗌

We will contact you to discuss your support requirements. Any information that you provide will be kept private and will not be passed to anyone without your consent.

However, staff at this organisation are concerned that information is not getting through to the Learning Support Coordinator.

I think people are now falling through the net.

This illustrates the importance of ensuring a holistic response to encouraging disclosure. As we saw above with MIS, it is important that any change does not happen in isolation but is considered alongside other disclosure processes. Producing disclosure procedures that identify how different processes link together will help resolve this issue, and this is discussed in Section 7.

- Have you reviewed questions on application, enrolment and other forms that learners complete, to ensure that there is:
  - □ a focus on the support that can be offered
  - a discussion of the benefits of disclosure
  - an avoidance of 'labels'
  - □ room for examples to be given, if the word 'disability' is used
  - no breach of the Data Protection Act regarding sensitive information
  - □ clarification about what will happen if a learner discloses?

The language used, of course, is not just restricted to the forms that learners are asked to complete. One project site realised that in looking at its enrolment form, they were not just looking at the appropriate use of language in a small section on the form but were, in fact:

Looking at radical institutional change including the language used in much of our promotional literature.

Have you reviewed the use of language elsewhere, for example in promotional literature?

### Statements on enrolment and other forms

Some providers ask for statements to be signed on forms such as enrolment forms and medical health questionnaires, or have statements in policies such as data protection policies that clearly breach the learner's rights to confidentiality regarding their impairment. Many have their origins in the model data protection policy contained in the Association of Colleges (AoC) good practice guide for the sector. There is a specific section in this model policy (page 41) which states:

The EI (educational institution) will also ask for information about particular health needs, such as allergies to particular forms of medication, or any conditions such as asthma or diabetes. The EI will only use the information in the protection of the health and safety of the individual, but will need consent to process in the event of a medical emergency, for example.

Therefore, all prospective staff and students will be asked to sign a Consent to Process form regarding particular types of information when an offer of employment or a course place is made. A refusal to sign such a form can result in the offer being withdrawn.

The model policy later states a clause 'without good reason', to help clarify a refusal to sign the form; however, this is open to misinterpretation and therefore misuse. In addition, where colleges have reproduced the above statement for enrolment and other forms and policies, this clause is often missing. For example, one organisation has questions asking if a learner has various impairments and then asks the learner to sign the following statement:

# **Example 16**

'I declare that I have answered the above questions honestly and fully and that I am not otherwise aware of any physical or mental disability which will, or may, affect my working capacity. I realise that any false or incomplete statement could result in my being asked to withdraw from the course'.

One college has an enrolment form that asks a learner to disclose an impairment by ticking a box (see example 9). The bottom of the form contains the following statement:

# Example 17

I agree to XXXX (name of college) processing my personal data, including data about my physical or mental health contained within this form, or other data which XXXX (name of college) may obtain from me or other people.

```
Name
```

Signature

#### This enrolment cannot be accepted without your signature.

Statements such as this not only breach a learner's right to confidentiality but do much to harm a learner's perception of the atmosphere and culture of an organisation.

In fairness to the Association of Colleges (AoC), its good practice guide was published before DDA Part 4 became law. However, many organisations have produced their own data protection policy and / or included associated statements on application or enrolment forms or other forms such as medical questionnaires, based on this model policy. The practical implications for this include:

- the need for providers to rigorously audit all policies, procedures, associated documentation and processes in the light of the DDA and the Freedom of Information Act
- the need for robust training so that all staff are clear on the requirements of the DDA Part 4, the Data Protection Act and the Freedom of Information Act.

Organisations have other types of unhelpful statements on forms. For example, one college has the following statement on its enrolment form:

## Example 18

Please let us know if you have a disability or learning difficulty. We recognise that you have the right not to disclose but the college cannot be liable for not providing support if you withhold this information.

Do you have a disability or learning difficulty? 
Yes No

Apart from the fact that this statement is false, such disclaimer statements are unnecessary and unhelpful to include on forms.

- Have you eliminated any statements from application, enrolment and other forms, such as medical questionnaires, that breach a learner's rights to confidentiality?
- Have you checked that any information provided by learners when completing medical questionnaires is accompanied with clear information on what will happen to this information, and also accompanied by meaningful consent from the learner to pass such information on to others? (see Section 6)

#### Interview processes

Even if there is no indication of an impairment on the application form, staff should discuss all possible support available and provide an opportunity for disclosure during the interview process, recognising that many impairments are 'unseen'.

One college has a prompt on interview paperwork about the need to discuss additional support options. However, there was inconsistent practice, for example some staff saw this as an opportunity to explore only literacy and numeracy support requirements. They have revised their interview paperwork and produced associated guidelines for staff on what to do if a learner discloses. It is important that such guidance for staff makes explicit the need to reassure learners that identification of support requirements is a process that is separate to any decision-making process on the appropriateness of a particular course. It might be that such a discussion takes place at the end of the interview process.

One college has an admissions team responsible for interviewing all applicants. They routinely discuss, with all applicants, the adjustments that can be made for disabled learners, and then ask 'would any of this be of interest to you?' This same college changed the question on the enrolment form to focus more on the support provided and the benefits of disclosure. Disclosure rates during admissions have increased considerably as a result of these changes.

- Do you ensure that support options are routinely discussed with all learners, and an opportunity is provided for disclosure, during the interview process?
- Have you produced guidelines for staff involved in the interview process?

# **Enrolment processes**

One adult and community learning (ACL) provider carries out a large number of telephone enrolments, and staff were anxious about encouraging disclosure over the telephone, for fear of causing offence. The organisation produced disclosure procedures that included a script for staff to use during a telephone enrolment when asking about possible support requirements. The support available for disabled learners is described and the applicant is then asked:

Would you like our learning support officer to contact you, in confidence, to discuss options or can we send you further information in the post?

A college provides the following prompts for admin staff during online enrolment:

Additional support enrolment messages:

- Can have a private chat with additional support team.
- Will not affect your right to access the course of your choice.
- All information is confidential and will not be passed on without your permission.
- Help you to achieve the best of your ability.

One college has created a 'final checking desk' where all learners go following completion of their enrolment form, before paying fees. The desk has staff from additional support who are actually just checking the 'disability' disclosure question to ensure this is completed and to offer confidential interviews for any person interested. The staff appreciate that learners do not have to complete this question, and are not coerced to do so.

One organisation was concerned with issues of confidentiality during busy online enrolment processes. It created well publicised spaces for a confidential discussion called 'confidentiality booths'. Another organisation has signs on enrolment desks that state 'please ask if you would like to talk to me in confidence'.

Do you ensure that learners have an opportunity to discuss their impairment with staff, in confidence, during enrolment?

One adult education organisation delivers provision through six main sites, as well as a host of smaller venues. While every learner who makes a telephone enquiry or makes enquiries at one of the centres is asked if they require additional support, staff found that procedures after that initial enquiry were ad hoc and varied from site to site. Research revealed that one site actually had a very good system in place to follow through this initial enquiry, whereby learner details were recorded and kept in a student support folder and these learners were contacted to discuss the kind of support they might benefit from.

If your organisation has more than one centre, are you aware of the disclosure and support processes that take place at these? Do you ensure that there is consistency in practice?

# 5 Ongoing opportunities for disclosure

Learners may choose not to disclose an impairment during the admissions process for a variety of reasons. They may feel that their impairment will have no impact on their study, for example, or they may be concerned that their impairment will jeopardise their chance of a place on a course. They may worry that they will be treated differently to others. They may have past experiences that influence their decision not to disclose or they may fear stereotypical reactions, particularly for impairments that frequently trigger stigma and prejudice, such as a mental health difficulty. In the DVD 'Learner's Experiences'<sup>3</sup>, a learner is asked why he didn't disclose on the enrolment form.

I didn't answer it because I thought it might be a negative effect on me for not going onto that course... they might ask me that you're dyslexic, you won't be able to do it because of the number of exams and the number of questions... so ... I skipped that question.

It is therefore important to create ongoing opportunities for disclosure, particularly before or at key events such as induction, exam registration, trips, work experience or before the setting of major course work. Learners may choose to disclose during their course because, for example, their personal circumstances change, they develop an impairment or a condition changes. They may form stronger relationships with staff, they might feel more confident that disclosure at this time will not lead to discrimination, or course requirements such as assignments may highlight issues that a learner wishes to discuss.

<sup>3</sup> This DVD was published by the LSDA in June 2004 and a copy sent to all FE and VI form colleges, ACL and WBL providers.

### **Tutorials and induction**

Induction can provide an opportunity to disclose. One college has guidelines for staff that cover aspects which should be discussed during induction, including the support that can be offered to learners with disabilities and learning difficulties, and who learners can see for further information. One organisation has a learner induction questionnaire that confirms that such a discussion has taken place. One college provides students with a course-specific student handbook which is discussed during induction. The handbook has a number of statements common to all courses, including two paragraphs on the support available for disabled learners, and contact names for further information.

Do tutors ensure that all students are offered an opportunity to disclose during induction?

One organisation has focused on the ways in which the tutorial system can provide ongoing opportunities for disclosure, particularly during one-to-one reviews. The following statement is included on the Individual Learning Plan (ILP) review form which acts as a prompt for discussion between a tutor and a learner.

## **Example 19**

We aim to support all students with learning difficulties and disabilities. We respect your rights to confidentiality. If you tick the box below, we will arrange for a confidential interview with the Head of Student Support to discuss additional support or adjustments. Following interview, we will not pass information on about your disability to anyone without your consent.

Piloting this form in just one curriculum area resulted in three new disclosures. Another organisation has also modified their one-to-one tutorial review form, not just to encourage disclosure but also to monitor adjustments by teaching staff for disabled learners who are not receiving additional support. There are six prompts on the form related to learner progress, previous review actions, etc; one of these prompts is specifically geared to learners with disabilities and learning difficulties.

## Example 20

Are the current arrangements for support effective? Do the adjustments that teaching staff make and / or the support that additional support staff provide, meet your requirements?

If you are not receiving support, would a discussion of what is available be helpful to you?'

Do you have strategies in place to encourage disclosure during tutorial sessions?

# **Examinations**

One organisation was concerned about the number of late disclosures to examinations staff. They revised their processes to give an opportunity for disclosure on the exam registration form which learners are asked to complete. They also produced an accompanying leaflet which discusses the adjustments that can be provided for disabled learners during examinations and where learners can go for further information. Tutors discuss this leaflet with all learners during the exam registration process. Examinations staff also have systems in place to better anticipate late disclosure.

Do you have strategies for encouraging disclosure before examination registration?

# Trips

Many organisations ask learners to complete a questionnaire prior to an external visit. There is an opportunity to ask a question that encourages learners to disclose on such a form; again it is helpful if this question focuses on the benefits of disclosure and the support that can be provided by the organisation. It should be remembered that information about an impairment cannot be passed on without consent and so it is important for the form to explain what will happen to the information released and how the learner will give consent (see Section 6).

- Have you reviewed forms used for educational trips and visits to ensure that an opportunity for disclosure is provided?
- If learners disclose on such forms, do you ensure that they have an opportunity to have a private discussion on what this means and to give meaningful consent before this information is passed to relevant staff?

#### **Work experience**

There are two issues related to disclosure when considering work experience. Firstly, to provide a further opportunity for a learner to disclose prior to the arrangement of work experience. Secondly, to encourage a learner to consent to information about support requirements to be passed to the employer. One project site developed an individual action plan to act as a tool for planning and communication between the learner, the education provider and the employer. They recognised that such a tool would be of most use if introduced to the employer at the beginning of a placement.

It is helpful because it supplies me with lots of information about the student, I can tell from this that I could leave him working on his own for short periods of time. The assessment about facts, feelings and future; that's really useful to me, I can tell the student is interested in getting a full-time job. What I really like is the bit about negative feelings, it's important to know that if he gets easily stressed then I can avoid high-pressure sites for him.

A learner may be reluctant to disclose their impairment to employers for similar reasons to those identified in Section 4, such as concerns that they will experience discrimination or jeopardise their opportunity for work experience. A learner's rights to confidentiality should be respected, although you will obviously wish to discuss options and implications with the learner. For example, a learner with dyslexia who wishes to keep this confidential may be happy for you to explain to the employer that the learner would find it difficult to take written messages at a hairdressing salon and could this be avoided? Where learners are working with children or other vulnerable people, or equipment than can prove hazardous, there may be health and safety and other factors that need to be considered. It is important to carry out an individual risk assessment that seeks to include rather than exclude the disabled person. It can be all too easy to use the excuse of 'it's against health and safety' or to have blanket health and safety policies or risk assessment processes. You may find the following guidance document useful:

Rose C (2005). 'I don't want to sue anyone... I just want to get a life.' Inclusive risk assessments. Guidance for colleges and other post-16 providers in implementing the Disability Discrimination Act. London: LSDA.

Are learners given a further opportunity to disclose and to discuss any concerns when work experience is being organised?

#### **Avoiding intrusion**

The danger with ensuring that learners are provided with a number of opportunities to disclose is that staff may 'over ask'. For example, one project site commented:

There is some anxiety in that encouraging students to declare a disability they may be asked this too often, especially if they have already declared. This may happen if the interviewing tutor is not the same person who enrols the student, for example.

In practice, this means that providers must find the balance between encouraging learners to disclose any individual support requirement and avoiding an approach that could be perceived as repetitive and intrusive. They should also ensure that effective mechanisms for passing on information are in place so that all relevant staff are informed as quickly as possible.

Do you ensure that tutors do not 'over ask' learners about their impairment?

#### **Ongoing opportunities for part-time courses**

Part-time courses offered by ACL providers or colleges rarely have formal tutorial time or structured one-to-one tutorial reviews. However, it is important that tutors provide opportunities for disclosure after enrolment and if a learner does disclose, arrange for a private discussion about the kind of support that a learner requires. This might be a very small adjustment, such as providing large print handouts for a learner with a visual impairment. It is also important that tutors ensure that they make time during the course to regularly review the support provided with the learner.

Tutors should be aware of colleagues in the organisation they can turn to, with the learner's consent, if they are unable to meet the learner's requirements.

- Do all tutors provide opportunities for learners to disclose after enrolment, for example at induction and exam registration?
- Are all tutors aware of who in the organisation they can turn to for advice and support?
- Do all tutors recognise their own role and responsibility in making reasonable adjustments for disabled learners?

#### **Appropriate approaches**

This is not just about ensuring that ongoing opportunities exist for disclosure in a confidential setting. This is also about ensuring that the appropriate approaches, attitudes and atmosphere are in place, to help a learner feel safe to disclose. One project site (college) conducted interviews with personal tutors and noted:

Great emphasis was placed on the tutor-student relationship that was developed, particularly during induction and the first half term. It was felt that this was the basis of creating an atmosphere which was open and honest and students felt comfortable in discussing sensitive issues.

One project site (ACL provider) made the point:

The role of the tutor is vital. Everything seems to come back to this. The tutor needs to engage in communication with learners, to give them the information and encourage disclosure of their needs. The tutor's response is vital; it must be positive and encouraging, not negative or dismissive. Learners quickly read into a tutor's response a negative message, intended or not, which affects their future attitude and confidence.

#### **Disclosure via a third party**

Providers are placed in a difficult position if a learner does not disclose an impairment yet there is indirect disclosure, perhaps because information is received that indicates an impairment. One project site gave an example of this with an applicant who was a pupil at a school for children with Asperger's Syndrome. He was also attending the local art college for one day a week.

We sent to both institutions for information on providing appropriate support. In both cases the advice was centred on the implications of Asperger's Syndrome. He did not declare anything on his application form. The applicant's mother came to interview and would not let him discuss any support needs or accept the provision of an LSA (Learning Support Assistant) for the group. There are no easy answers to this difficulty and the illustration raises issues for providers in responding sensitively to the views of parents and carers, while keeping the learner's views central to any decision-making process. However, the illustration also highlights the need for all staff to be fully aware of the variety of adjustments that might be appropriate for learners with a range of impairments. We can put in place good processes and procedures to encourage people to disclose, but we need to recognise that a number of people will still not disclose, and that is their right. We should all be aware of good practice in supporting learners with a range of impairments such as mental health difficulties, Asperger's Syndrome and dyslexia, so that even if people do not disclose we can still provide a supportive environment. It is important to appreciate that a responsible body might not formally have to be told that a learner has an impairment before making an adjustment, especially if the impairment is obvious.

This situation also raises issues about passing information between organisations such as a school and a college. It is inappropriate for schools to pass information to a post-16 education provider without the consent of the disabled person. It is helpful for post-16 education providers to work closely with partner organisations to develop disclosure and confidentiality policies and procedures, as there may be opportunities to educate partner organisations in the process.

Sometimes the friend or parent of a learner will want to disclose their friend or son or daughter's impairment, often out of a genuine concern that support is likely to be required or prove beneficial. However, unless the learner does not have the ability to discuss his or her impairment, for example a learner with a profound and complex disability that makes communication very difficult, other people do not have the right to disclose on a learner's behalf. It is important to make this clear to the friend or the parent, while at the same time suggesting that they encourage their friend or son or daughter to disclose, perhaps by stressing the benefits and also by explaining who the learner can see to have a confidential discussion on the support that the organisation can provide. The learner may appreciate the use of an independent advocate.

Do you have an ongoing staff development programme to raise awareness among staff on how best to support learners with a range of impairments such as learners with Asperger's Syndrome and learners with mental health difficulties? Do you work in partnership with partner organisations such as Connexions and feeder schools, to facilitate the sharing of information and the transition process for learners? Do you use this partnership to ensure that you all have a shared understanding of the requirements of the DDA and the Data Protection Act regarding disclosure, passing on of information and confidentiality?

# 6 Respecting confidentiality

#### **Consent forms**

A number of organisations have produced consent forms for learners to sign, in order to obtain meaningful consent to pass information on to other staff. When thinking about what a consent form should look like, it is helpful to remember that the underpinning ethos of the Data Protection Act is one of openness, honesty and transparency about the information that is held on people and what is done with that information. A consent form should therefore clarify what information is going to be passed on to staff, focus on the adjustments that the organisation will make to meet the learner's requirements, and allow the learner to decide who should have access to this information, for example teaching staff and/ or personal tutors.

The following are examples of extracts from consent forms used by providers that are unhelpful, as they do not follow these basic principles.

#### **Example 21**

Brief outline of disability

I give my permission for this information (when appropriate) to be passed on to teaching staff, examinations, college nurse and other relevant staff.

#### **Example 22**

If any of the following apply to you, please tick the box

D1 Visual impairment	
D2 Hearing impairment	
D3 Disability affecting mobility	
D4 Other physical disability	
<b>D5</b> Medical condition eg epilepsy, asthma, diabetes	
D6 Emotional /behavioural difficulties	
D7 Mental health issues	
D8 Temporary disability after illness / accident	
D9 Profound complex disabilities	
D10 Multiple disabilities	
D11 Other disability	
L1 Moderate learning difficulty	
L2 Severe Learning difficulty	
L3 Dyslexia	
L4 Dyscalculia	
L5 Other specific learning difficulty	
L6 Multiple learning difficulties	

We can only give the right support if we can pass information about your disability and / or learning difficulty to other members of staff. Under the law, we need your consent to do this. Please tick the box below if you are happy for us to do this. We will only tell those staff who can support you during your time at College.

- Yes, I am happy for staff to be informed.
- No, I am not happy for staff to be informed and I appreciate that this may mean the college will be unable to give me full support for my learning.

#### Example 23

I agree to the information given in my form JP18 (student assessment) being passed and processed by the following staff:

I understand that the information disclosed will only be used to make necessary adjustments regarding the provision of support and also to monitor support across the college.

#### Example 24

I agree to the College recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in the statement above, and my consent is conditional upon the College complying with its duties and obligations under the Data Protection Act.

Signature

Date

## Example 25

Any disclosure of information to third parties will be both relevant and necessary to further your case. A decision to limit disclosure may result in your need not being met appropriately or sufficiently.

I agree to the sharing of information in relation to my special need.

□ I **do not agree** to the sharing of information in relation to my special need.

Student signature:

Date:

These examples are unhelpful for one or more of the following reasons:

There is a focus on the learner's impairment, rather than the support that the organisation will provide. In other words, a medical model rather than a social model approach is taken. One learner at a college, looking at example 22, made the comment: I do not want to be seen as a label. What has this got to do with me as a person? What does D11 mean anyway (referring to the ILR college code on the form).

- There is a lack of clarity on who will be informed and a lack of options for the learner to limit circulation of information to specific staff. For example, a learner may disclose a mental health difficulty and only be happy for his or her personal tutor to be informed.
- There is a lack of clarity on what information is being shared.
- There are meaningless aspects, for example unfamiliar letters identifying forms or unhelpful, learner-unfriendly language, for example 'processed' and 'duties and obligations under the Data Protection Act'.

Example 22 includes ILR (Individualised Learner Record) data fields in a consent form to make capture of this data easier for Management Information Systems (MIS). This can lead to confusing and unhelpful labelling, rather than focusing on what the organisation will do to meet the support requirements of the learner.

Having a visual impairment, experiencing a mental health difficulty or acquiring a medical condition are all 'labels' that might be attributed to learners, but provide little or no indication of the impact of an impairment on learning or the organisational barriers that must be removed to ensure an equitable educational experience. Identifying a 'label' for a learner takes the focus away from organisational responsibilities to ensure disability equality, reinforcing the medical model of disability. It might be argued, therefore, that the specific nature of an impairment is irrelevant for the organisation in the planning and delivery of services, providing that disability equality is embedded across the whole organisation and the needs of disabled people are effectively anticipated and met on an individual basis. However, organisations may have a laudable vision for disability equality, but data monitoring is one way to ensure that inequalities do not exist in practice. This introduces a tension between striving to adopt a social model of disability and accepting that the obstacles that disabled people face are largely the result of organisational barriers, while trying to capture data for the ILR that can be used by both the organisation and the LSC to continually improve disability equality. Furthermore, data monitoring is a statutory requirement within the Duty to Promote Disability Equality as part of DDA 2005.

It is important therefore that data within MIS is accurate so that statistical analysis of performance is meaningful and accurate returns are to be made to the LSC. However, using a consent form to gather this information is inappropriate; there are alternative ways to provide this information for the organisation's database. For example, the Learning Support Coordinator in one organisation has a separate form that is easily completed after an assessment of support has been conducted, where the correct ILR field is highlighted and sent to MIS. Another organisation has learning support staff that carry out an assessment of support requirements with the learner and obtain consent to pass information on to others, including MIS. After the interview, they then enter the information directly onto a closed database that has been set up to interface directly with the appropriate ILR fields that identify impairment.

#### Other pitfalls to avoid

Some colleges have not produced a consent form, and instead rely simply on a learner signature at the bottom of support assessment paperwork. This can lead to both unnecessary and confidential information being passed to staff. The purpose of carrying out an assessment is to determine what the organisation will do to meet learner requirements, by identifying all relevant information from the learner, from screening tests and reports and from other agencies such as feeder schools and Connexions. Effective assessment will take time and may involve the collection of a considerable amount of information. It is unlikely that all this information is relevant or appropriate for staff, such as those who teach the learner. Learners may well not want all information discussed during the assessment to be passed on to others. As we discussed earlier, the purpose of a consent form is to help a learner to feel in control of the information they disclose and confident that they understand and agree the information which will be passed on and to whom. The following extracts of provider consent forms help address the above difficulties by, for example:

- focusing on the support requirements necessary for staff to be aware of, rather than focusing on a learner's impairment
- explaining why a learner is being asked to sign the form
- providing flexibility by allowing a learner to change their mind at any time
- allowing a learner to have control over who will and who will not have access to the agreed information.

#### **Example 26**

In order to make adjustments or arrange additional support, we need to let other staff know about your requirements. We respect your right to confidentiality and assure you that the information that you allow us to pass on to others will be handled in a sensitive and discreet manner. We need your permission to pass information on to other staff.

## Example 27

We can only give your information to other people if you agree.

## Example 28

I am happy for the following information to be passed on about my support requirements.

## Example 29

We have agreed your support and now need your consent to pass this information to other staff.

I am happy for the following people to be told.

## Example 30

#### **Option B**

I agree for the following people to be informed:

Staff who teach me	
My personal tutor	
Additional Support staff	
Course Team Leader	
Examination staff	
Examination awarding bodies	
Finance and administration staff	
Reception staff	
Careers, guidance and welfare	
Staff who are part of the first aid team	
Anyone else you think should be informed	

## Example 31

We need your permission to let staff and others know about your support requirements

My main support requirements are

You can tell

#### Example 32 – at the bottom of the form

If you change your mind about anything on this form, please see XXXX (name of staff member) in Room XXXXXX.

One organisation has included a 'student comment box', to give a learner the opportunity to have a say about the information that went to teaching staff. Learners have included statements such as:

Please don't draw unnecessary attention to me when you give out my handouts as I get easily embarrassed (learner with a visual impairment).

If I appear withdrawn, please let me sit quietly (learner with a mental health difficulty).

You may also need to document on a consent form who should not know, for example other learners.

The process of obtaining consent should be a positive experience for the learner. One college involved learners in the development of a new consent form that contained one of the above extracts, and learners made the following comments:

I think this form is really helpful because I don't want everyone to know, and this makes me feel confident that only a few people will know and everyone won't be talking about me.

It helps me feel reassured. It's nice to know that staff will know. I don't want to keep having to go to people – I don't like to feel I'm a burden cos it's like, well embarrassing. It's really important for people to know before I come into their class so I don't have to keep telling everyone.

- Do you have a consent form that a learner signs to give their permission for information to be passed to appropriate staff?
- Is your consent form simple to understand and written in learner-friendly language?
- Does your consent form
  - provide an opportunity for the learner to restrict the information passed on to specific staff
  - focus on the support required and the adjustments that the organisation will make, rather than the learner's impairment
  - explain what information is being passed on?
- Have you engaged with learners on the wording and design of your consent form?

#### **Meaningful consent**

A number of colleges have learners under 16 (14–19 provision) and there are anxieties about learner rights versus parental rights. Specific training is required so that staff appreciate the implications of the Gillick court case (1985) and the Children's Act 1989. Briefly, there is the need to recognise that parents do not generally have the right to override a learner's request for confidentiality, providing there are no serious and immediate threats to that learner or another learner's health and well being. A learner's request for confidentiality should be respected above the desire or potential desire for parental knowledge or influence, providing the learner understands the meaning of their request. The judge in the Gillick court case identified that children generally reach this stage of development at an age of around 12. There is a potential tension here between respecting a learner's rights to confidentiality and ensuring a learner-centred approach where parents are recognised as valued and active partners. However, it is important to keep the learner's views central to any decisions that are made.

Secondly, some staff have expressed concern for learners who would have difficulty in providing meaningful consent, perhaps because of a profound and complex learning difficulty. While it is acceptable for a parent or carer to give consent where it is not possible for a learner to do so, we have a responsibility to ensure accessible versions of consent forms are available to provide an opportunity, wherever possible, for a learner to give meaningful consent. If a parent or carer signs a consent form on behalf of the learner, this should be carried out in the presence of the learner.

Do you have accessible versions of your consent form?

#### **Respecting confidentiality**

It is important that opportunities for disclosure be accompanied by a respect for a learner's rights to confidentiality. One organisation, for example, asks learners during an induction session to complete a form that asks for details of any impairments, medical conditions, and medication. Learners should not be expected to disclose in front of their peers in a packed classroom. As one learner stated, when asked about the process 'It isn't very confidential'.

It is important to explore options with learners who request confidentiality. For example, it may not be necessary for staff to know the full details of a learner's impairment and to just be aware of the adjustments that they need to make. It could be arranged that only certain staff will be given the agreed information. Discussing possible alternatives, while at the same time making it clear that a learner's rights to confidentiality will be respected, will make it far more likely for a learner to be receptive to exploring ways for adjustments to be made which preserve their request for confidentiality. It perhaps goes without saying but staff must recognise the right of a learner to confidentiality and avoid persuasion when asking a learner to sign a consent form.

Certain exceptional circumstances may allow the release of information, for example when there is an immediate and serious threat to the personal safety of the learner or the safety of others. However, it is important to stress that these are likely to be rare and exceptional circumstances. If staff are anxious they can talk to others without disclosing the identity of the learner.

Particular courses involving care for the public, such as childcare or care of the elderly, may have additional criteria with regard to confidentiality exceptions. In these circumstances it is important that clear information is provided about when these exceptions may have to be implemented.

#### **Disclaimer statements**

Some providers have included a disclaimer statement as part of the consent form, or have a separate disclaimer form. Section 8.11 of the Disability Discrimination Act Part 4 Code of Practice states that any form used to prevent someone from making a claim of discrimination is invalid. The request for complete confidentiality that may accompany a learner's disclosure should be respected and options and implications should be discussed, so that a learner is able to make a fully informed decision. Any written record of such a discussion should be seen as an 'agreement' by both parties that the right of the learner to complete confidentiality will be respected. It is helpful if a review date can be agreed, to provide an opportunity for the learner to change their mind at a later date. Disclosure procedures should identify how these records will be stored in order to ensure confidentiality is preserved (an example is provided in Section 7 – see example 33).

# 7 Developing disclosure and confidentiality procedures

Effective disclosure and confidentiality procedures brings clarity to the process of encouraging disclosure, obtaining consent and passing on information to relevant staff. They can help to ensure that:

- all staff know how to respond if a learner or potential learner discloses an impairment, and to whom, and how, with the learner's consent, information should be passed on
- all staff understand the appropriate responses if a learner requests confidentiality.

Further education colleges, sixth form colleges, and adult and community learning providers have asked for my consultancy services to provide support in producing disclosure procedures. Although the procedures have been highly specific to each organisation, the process of developing these has been similar. The purpose of this section of the guidance document is to describe this process.

## Stage 1

The first stage in developing a disclosure and confidentiality procedure is to identify a team of relevant staff who can provide input into current practice. For a college, this generally means representatives from:

- admissions
- learning support
- front line support staff (eg reception, finance)
- management information systems
- personal tutors and teaching staff.

For an ACL provider, this generally means representatives from staff who are:

- tutors (full-time and part-time)
- programme leaders
- staff responsible for DDA implementation/disabled learners
- front line staff, particularly staff involved in enquiries and enrolment.

It is also important to involve learners to determine their perceptions of the process and to promote their input into policy and procedure development, as they are able to provide a valuable and unique insight. Furthermore, the Duty to Promote Disability Equality, which comes into force in December 2006, requires the active involvement of disabled people in any new policy and procedure development.

It is helpful to approach learners who have a range of impairments, such as learners with a physical or sensory impairment, and learners with an 'unseen' impairment, such as epilepsy or dyslexia. It is also helpful if learners are identified who disclosed at various stages in their learning journey, for example during the admissions process or on-programme.

#### Stage 2

The second stage is to identify current practice. A range of opportunities for disclosure are explored, for example at application, interview, enrolment, or on programme disclosure to a tutor, member of reception or someone in the learning resource centre. Third party disclosure by, for example, parents, Connexions and feeder schools can also be explored. Each process is discussed and drawn up as a flowchart on a flipchart. Issues are flagged on the flipcharts so that they can be returned to at the next stage.

The advantage of flowcharts is that they help to describe the activities and tasks in a process, how these link together, the sequencing of operations and the key decision points. Few people understand the entire process within which they work or how their own actions affect other parts of the process, and the use of flowcharts helps people to see their own role and the ways in which they interface with other key people and events.

This stage often highlights a number of gaps and flaws, which have included:

- poor communication
- responsibilities of different staff unclear
- poor or inconsistent processes for informing MIS (management information systems) if disclosure takes place after enrolment
- confusion among staff, such as teaching staff, about how to refer learners for an assessment of support requirements, following disclosure
- lack of monitoring, particularly if learners rely on teachers to make adjustments rather than on learning support assistants
- inappropriate mechanisms for obtaining consent, lack of clarity in obtaining consent or non-existent consent processes
- inconsistency in interview practice in discussing support options and availability and encouraging learners to disclose
- lack of robust mechanisms to inform relevant staff, such as tutors, of a learner's support requirements
- Iack of staff awareness of the legal requirements and implications of the DDA and the Data Protection Act, regarding disclosure, passing on of information and confidentiality.

#### Stage 3

Discussion and analysis of the various processes with staff provides an opportunity to remedy issues and identify areas for improvement. The third stage is therefore to identify revised processes, again, summarised in a series of flowcharts. In the case of a number of ACL providers, or part-time provision within colleges, there might not be any disclosure procedures in place and this stage helps identify new systems that are robust yet manageable. Associated documentation is either revised or produced, such as consent forms. When you work in an organisation, it can be difficult to stand back and see the bigger picture – the 'not being able to see the wood for the trees' conundrum. You may also be unaware of good practice in other organisations. You might therefore want to consider the use of someone external to your organisation such as a senior manager from another education provider, or a consultant with DDA expertise.

#### Stage 4

The fourth stage is to produce disclosure procedures. These should provide clarity about how the organisational policy on disclosure will be implemented. A framework for a disclosure and confidentiality policy was discussed in the initial guidance document (Maudslay and Rose (2003), Disclosure, passing on of information and confidentiality), and an adapted version is included in Appendix B.

The procedures should include the flowcharts discussed above and should also describe the monitoring and evaluation mechanisms to ensure that the procedures are operating effectively in practice (see next section of this report). Learners are invaluable in helping to produce relevant paperwork, such as a consent form or a confidentiality agreement.

Examples 33 and 34 illustrate flowcharts taken from disclosure procedures for a college and an ACL provider respectively. Flowcharts were produced with visio software, using three key symbols:



This symbol represents an activity, operation or step in the process.



This symbol represents a decision point. Each diamond has a question that can be answered 'yes' or 'no'. This symbol shows the direction of the process.

#### Stage 5

The fifth stage is to consult with staff in a variety of job roles and at different levels on a first draft of the procedures. Staff support what they help to create and their active involvement in the process will aid implementation. It is also important to discuss this with disabled learners. Feedback from both groups will help to refine the first draft. I have generally found that one or two revisions are necessary before staff and learners are happy for these to be implemented.

## Stage 6

The sixth stage is to introduce procedures and associated forms to staff, for example during staff development sessions. Staff have the opportunity to explore issues around DDA Part 4, the Data Protection Act, disclosure and confidentiality and feedback at these sessions can also fine-tune the new documentation. The procedures provide staff with the opportunity to better understand their role in the process and to see how their role relates to that of other key individuals.

The process does not end there. Like all procedures, it is important to monitor and evaluate to ensure that they are operating effectively in practice, and this is discussed in Section 8 of this report.

# Pitfalls to avoid when producing policies and procedures

There a number of pitfalls that organisations should avoid when producing effective disclosure and confidentiality policies and procedures. Firstly, avoid combining child protection, drug abuse and other unrelated disability issues into a single confidentiality procedure. Organisations should have a child protection policy and a drugs policy that address the issues of confidentiality within these contexts. It is often unhelpful and confusing to staff to combine these within a confidentiality policy that addresses the rights of disabled learners to confidentiality. For this reason, the skeleton disclosure policy and the skeleton confidentiality policy provided in the 2003 national guidance document have been combined into a single disclosure and confidentiality policy that deals solely with disclosure of an impairment (Appendix B). The second pitfall to avoid is having a paper or a process-driven exercise, rather than an outcome-driven exercise. Disclosure and consent is not merely about ticking boxes, filling out forms or following the process of a flowchart. It is about fully explaining the benefits of disclosure, respecting the rights of the learner to confidentiality and thereby dealing with the process of disclosure and consent with tact and sensitivity. Completion of a consent form with a learner is not about ensuring compliance with legislation. It is an opportunity to empower a learner, allowing the learner to be in control of the information they have released, confident that their rights to confidentiality will be respected and thereby contributing to the creation of a climate of trust and openness.

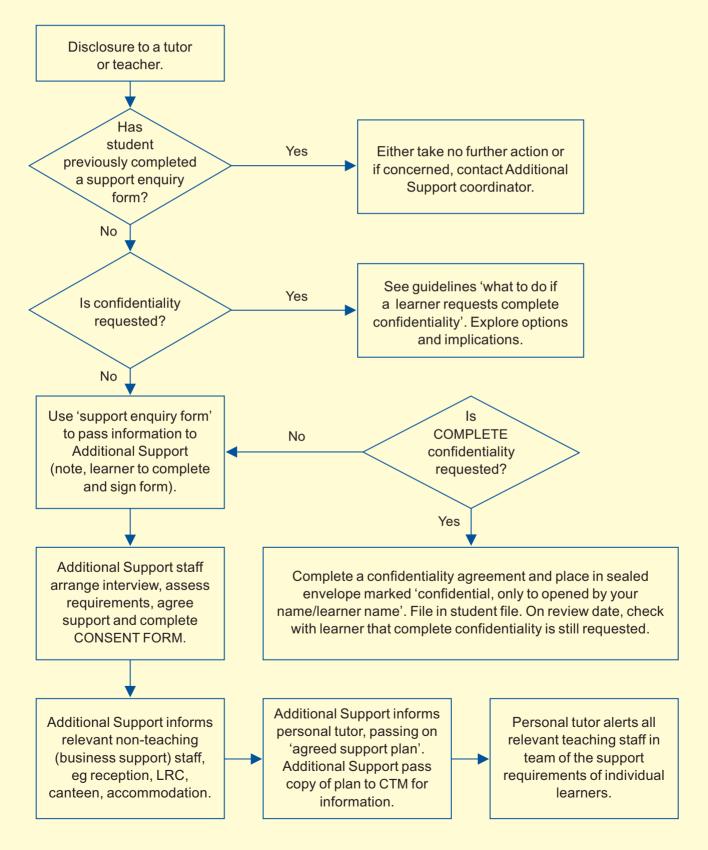
Thirdly, many colleges have adult provision and it is important that this is not neglected. Processes for disclosure for full-time courses should be transferred appropriately to part-time provision, such as evening classes.

- Have you developed a disclosure and confidentiality policy and procedure for full-time and part-time programmes that provides clear guidelines for staff? Are all staff, including part-time staff, aware of these?
- Have you used the process of developing procedures to address gaps and difficulties with current systems?
- Have you actively involved learners?

#### Example 33

Flowchart extracts from Chichester College disclosure procedures

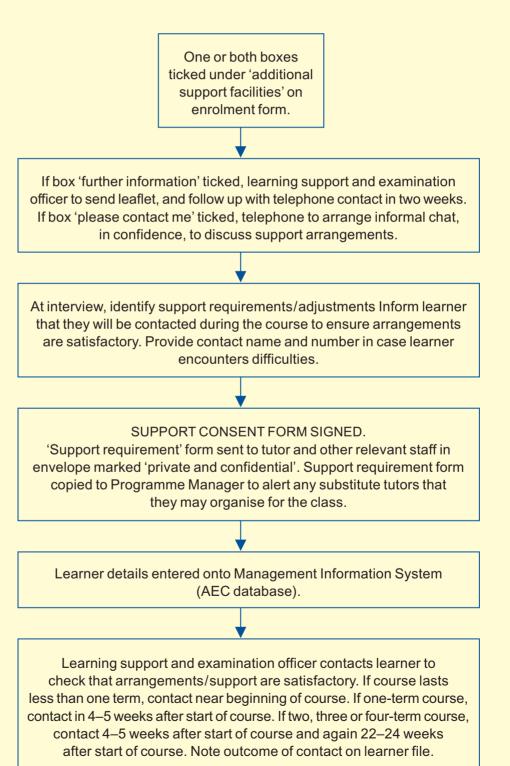
5. Disclosure on programme, to teaching staff



#### Example 34

## Flowchart extract from Merton Adult Education Service disclosure procedures

#### **Disclosure on enrolment form**



# 8 Embedding new procedures 53 in practice

When developing new policies and procedures, it is important to consider how these will be effectively embedded in practice. The following factors can influence the success or otherwise of this process:

- Staff must be able to see the benefits of the new policy and procedure. It is difficult to embed any new process if the benefits are not made clear to all.
- Staff at all levels should be involved in the development of the new policy and procedure. These are difficult to embed if they are written exclusively by senior management and presented to staff for implementation, without adequate opportunity for staff working at operational level to shape and develop the policy and procedure. They are also difficult to establish if they are produced without senior management involvement and support.
- Effective training and communication are critical to ensure staff awareness and understanding of the new policy and procedure.

These last two factors are discussed further below.

#### Senior/executive management support

Senior/executive management play an important role both in driving forward change and in removing barriers, for example helping staff to overcome caution or resistance to change. Their involvement is important in ensuring that new policies and procedures are not developed in isolation, but dovetail within the overall direction and vision of the organisation. Their involvement is also important to ensure that a strategic approach is taken to staff development (see below).

Have you had support and commitment from senior/executive management in formulating new policies and procedures on disclosure and confidentiality?

#### **Staff training and development**

Although many organisations have provided some form of staff awareness training for the DDA, the issues of encouraging disclosure, effectively passing on information and respecting confidentiality have often not been adequately addressed. In addition, staff may not have attended such training and therefore do not fully understand their role and responsibilities under the DDA and the Data Protection Act. One project site made the observation, for example, that:

Recruitment, marketing and CDS teams do not seem to be fully aware of their responsibilities in matters of disclosure and confidentiality. This will be addressed as a priority after the summer break. We have not yet reached the situation as an organisation where all members accept and embrace their responsibilities.

If the legislative requirements on disclosure and confidentiality are to permeate throughout an organisation, there will need to be a strategic programme of staff development. New disclosure and confidentiality procedures and processes can act as a pivot for further staff development, to help ensure that all staff are aware of their responsibilities in the organisation. You may wish to make use of the exemplar training programme, objectives and staff training materials that are contained in Appendix A.

An earlier section of this report noted that one project site effectively engaged staff in order to produce a policy and procedure for disclosure and confidentiality. Consultation involved a number of meetings, held over a period of months, with a range of staff with different job roles and responsibilities and levels of seniority. Further discussions took place during a variety of senior and middle management meetings. Full consultation took place during subsequent staff training sessions to which all staff were asked to attend.

The allocation of whole college inset training time to the Disclosure and Confidentiality Policy had a huge impact in making the movement towards the culture of disclosure a confident and cohesive one.

Have you arranged Disability Discrimination and Disability Equality training to address adequately the issues of disclosure and confidentiality? Have you used new policies and procedures as a pivot for further training?

#### Monitoring and evaluation of procedures

DDA Part 4 is clear that once a learner has disclosed an impairment, the onus is on the provider, with the learner's consent, to pass on appropriate information to relevant staff. This does not always happen. For example, one project site reported:

Several students have fed back that they feel that if information on their support needs was given to the person who interviewed them, they do not expect to have to explain this to everyone who teaches them. In one instance a student who has a medical problem gave the information that she has to make frequent visits to the hospital. She was extremely upset when she received a disciplinary letter because her attendance was below the expected norm. Another student, who declared dyslexia and ADHD and provided comprehensive reports, complained to his support tutor that his personal tutor could not have read his report because she was not following any of the recommendations and was criticising him for behaviour that was explained in the report.

Another project site discovered that:

One curriculum team has just filed all the information that they have been sent on students' support needs.

One learner commented:

I don't think some tutors have read the notes you've (Head of Learning Support) sent round.

One college found that learners, when given an opportunity to give feedback on their learning experiences, raised concerns that some teachers were not implementing adjustments. The learners had not felt assertive or empowered enough to report the problem. It had been assumed that the arrangements were working well as no complaints had been made.

It is therefore important that new policies and procedures identify the monitoring processes which ensures that procedures are operating effectively in practice. Example 34 illustrates how a monitoring process can be inserted into a flowchart (see last box in flowchart). However, monitoring arrangements are more commonly discussed at the end of a set of procedures. Consulting with learners about their experiences is an essential part of this monitoring and evaluation process. The process is not simply a means of improvement in itself but should lead to change, to continuously improve the experiences of disabled learners.

- Do your disclosure and confidentiality procedures make explicit the monitoring and evaluation processes, to ensure that procedures are operating effectively in practice?
- How do you consult with disabled learners? How might you do this more effectively?

## 9 Conclusions

This report has identified a range of issues for you to consider as you review practice within your organisation. I have inevitably focused on the need for clear, coherent and appropriate forms, policies and procedures and the need to engage with learners when establishing these. Ensuring a learner-centred approach is fundamental to all the themes in this report, and a crucial factor to consider when identifying appropriate and effective processes for encouraging disclosure, respecting confidentiality and passing on information to others.

However, it is actually relatively easy to create a suitable consent form or write a disclosure procedure. What is much harder to achieve, but worth striving for, is a consistent organisational culture and ethos which allows all learners or potential learners to feel safe to disclose and positive that their rights to confidentiality will be respected.

The culture and atmosphere at an organisation can play a vital part in encouraging a student to disclose... Students are far more likely to disclose information if they feel that they are in an organisation that has a welcoming atmosphere, an ethos that supports disabled people, and a value base that ensures that all disclosures will be treated with sensitivity and respect and used only for the benefit of students.... Encouraging disclosure, effective mechanisms to pass information on and respecting confidentiality are central to ensuring that all students with disabilities [and learning difficulties] have access to successful learning opportunities.

Maudslay and Rose (2003), p28

#### References

AoC (1999). *Data Protection in the Education Sector. A guide for good practice*. London: Association of Colleges.

DRC (2002). *Disability Discrimination Act* 1995 Part 4, Code of *Practice for providers of Post-16 education and related services*. Stratford upon Avon: Disability Rights Commission (DRC)

Faraday S and Maudslay L (2000). *FE college disability statements: an evaluation*. London: LSDA

Maudslay L (2004). *Responding to the cultural requirements of disabled learners from minority ethnic groups*. London: LSDA

Maudslay L and Rose C (2003). *Disclosure, passing on of information and confidentiality*. London: LSC

Rose C (2005). 'I don't want to sue anyone... I just want to get a life'. Inclusive risk assessment. Guidance for colleges and other post-16 providers in implementing the Disability Discrimination Act. London: LSDA

#### Appendix A Suggested training plan and case studies

#### **Staff development materials**

The following pages provide some exemplar materials that you may wish to consider using for staff development sessions. A possible two-hour workshop session may include the following:

- Introduction this is an opportunity to explain the purpose of the session and to place the session in context, perhaps by describing the staff development plan or the organisation's action plan for DDA implementation (5–10 minutes).
- PowerPoint presentation (Slides 1–7) this may take approximately 25 minutes. It is helpful if you provide specific examples from your own organisation, such as the strategies you have for ongoing opportunities for disclosure, and it is also helpful if you provide an opportunity for questions and answers.
- Scenarios to consider there are four that are tailored for either an FE or an ACL setting. This session should allow 30 minutes for staff to discuss the issues, and 30–40 minutes for feedback to the whole group.
- 4. Conclusions it is helpful to round up the training session by summarising the key issues raised by the session, perhaps identifying further work for the organisation in implementing these requirements, and ending with the final slide (8) of the PowerPoint presentation (approx 10–15 minutes).

Slide 1

# Encouraging disclosure, respecting confidentiality

#### **Disclosure**

The Disability Discrimination Act Part 4 says that, providing consent has been given, once one person in an organisation knows of a learner's impairment, the organisation as a whole is deemed to know.

Under the DDA Part 4, once one member of an organisation knows about a learner's impairment and the learner is happy for this information to be shared, then the whole organisation is deemed to know. The reasoning behind this is that organisation should have effective channels of communication so that information is passed on to appropriate staff. It should not be left to the learner to go to every relevant member of staff, informing them of their impairment / support requirements.

(You might want to provide a short explanation at this point about the difference between the medical model and social model of disability, and the difference between the words 'disability' and 'impairment' in the social model of disability. This provides you with an opportunity to stress the organisation's responsibilities to remove barriers and to ensure disability equality.)

#### Confidentiality

Data Protection Act

- Information about a student's impairment is classified as 'sensitive'.
- You cannot pass information on about a student's impairment without explicit informed consent from the student.
- DDA4 reinforces this right.

Under the Data Protection Act, medical information and information about a person's impairment is classified as sensitive. This means that following disclosure, information cannot be passed on to anyone else internally or externally without the learner's explicit informed consent. Under the DDA Part 4, a learner has the right to request that the existence or nature of his or her impairment be treated as confidential. This reinforces the requirements of the Data Protection Act.

# Disclosure, confidentiality and passing on information

- Disclosure could occur with anyone, for example a tutor, someone in the Learning Resource Centre, a member of reception.
- Following disclosure and consent, information must be passed on to the appropriate person in a secure manner.

The practical implications of this are that disclosure could happen with anyone, and it is important that all staff are clear on the process by which they obtain consent to inform others in the organisation, and to whom they should pass the information.

# What if you did not know that someone was disabled?

The organisation is responsible to be proactive in encouraging people to disclose in the following ways:

- marketing and communication
- admissions
- ongoing opportunities
- atmosphere and culture which is open and welcoming so disabled people feel safe to disclose.

The definition of a disabled person is broad, and includes learners with physical or sensory impairments and also learners with 'unseen' impairments, such as dyslexia, epilepsy or a mental health difficulty.

Effective marketing information, visible signs that diversity and disabled people are welcome, and appropriate admissions processes can do much to encourage a learner to disclose.

Lack of knowledge can be a defence, but only if the organisation can prove that it took 'reasonable steps' to find out about a person's impairment. Under the DDA Part 4, providers are expected to be proactive in encouraging people to disclose. This involves providing appropriate and effective opportunities for disclosure, not just during the admissions process but also at regular intervals throughout the course. Learners may choose not to disclose during the admissions process for a variety of reasons. They may feel that their impairment will have no impact on their study, for example, or they may be concerned that their impairment will jeopardise their chance of a place on a course. They may worry that they will be treated differently to others. They may have past experiences that influence their decision not to disclose or they may fear stereotypical reactions, particularly for impairments that frequently trigger stigma and prejudice, such as a mental health difficulty.

Effectively encouraging disclosure also involves providing an atmosphere and culture where learners with disabilities and learning difficulties are valued, information is dealt with sensitively, and confidentiality is respected.

#### What if someone requests confidentiality?

- A student has the right complete confidentiality.
- If a student requests complete confidentiality, information cannot be passed on from that point.

It is important that ongoing opportunities for disclosure be accompanied by a respect for a learner's rights to confidentiality. If a learner does request confidentiality, it is important to explore options. For example, it may not be necessary for staff to know the full details of a learner's impairment, but to focus instead on the adjustments that can be made. It could be made clear that only relevant staff will be given the agreed information. Discussing possible alternatives, while at the same time making it clear that a learner's rights to confidentiality will be respected, will make it far more likely for a learner to be receptive to exploring ways for adjustments to be made, while preserving their request for confidentiality.

A learner's rights to confidentiality, including complete confidentiality, should be respected. Certain exceptional circumstances may allow for the release of information, for example when there is an immediate and serious threat to the personal safety of the learner or the safety of others. However, it is important to stress that these are likely to be rare and exceptional circumstances. If staff are anxious, they can talk to others without disclosing the identity of the learner. Slide 7

# **Scenarios to consider**

This is an opportunity to discuss some of these aspects in groups, exploring the issues that arise from a series of case studies. (There are four to consider, tailored to either an FE or an ACL context.)

## Slide 8

'Encouraging disclosure, effective mechanisms to pass on information and respecting confidentiality are central to ensuring that all students with disabilities and learning difficulties have access to successful learning '

This quote is taken from the national guidance on disclosure (Maudslay L and Rose C (2003), *Disclosure, passing on of information and confidentiality*. London: LSC.)

The culture and atmosphere of an organisation can play a vital part in encouraging a learner to disclose. Learners are far more likely to disclose information about their impairment if they feel that they are in an organisation that has a welcoming atmosphere, an ethos that supports disabled people, and a value base that ensures that all disclosures will be treated with sensitivity and respect and used only for the benefit of learners. Effective marketing materials, visible signs that diversity and disabled people are valued, staff training and transparent processes are all factors that influence the atmosphere of an organisation.

# Workshop activity – FE

### Disclosure, passing on information and confidentiality

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

## **Scenario 1**

Bob is keen to study French at an evening class at his local college. He has a medical condition that means that at times he gets very tired. He feels that in general he will be able to manage in the two- hour sessions, but is worried that he might have to miss some classes and that there may be times when he cannot stay in the class for the whole two hours and might need to have a short break.

He hands in his enrolment form to the reception staff and tries to raise the issue of his condition. However, the member of staff is very busy and says her job is just to take in the forms, and any individual needs must be discussed with the class tutor.

Bob goes along to his first class. The tutor gets straight onto the business of teaching French and at the end she leaves very quickly. Bob has no opportunity to discuss things with her in private.

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

# **Scenario 2**

Jenny has been formally diagnosed with dyslexia while at secondary school, and receives considerable support that allows her to achieve reasonably well in her GCSEs. She applies for an A-level course at her local college but does not tick the 'do you have a disability' tick box on the application form, because she is extremely embarrassed by her condition and she does not want other learners to know about her dyslexia. Because she has not ticked the disability box on the application form, she is not asked if she has any additional support requirements at her interview. She is offered a place on condition that she achieves the GCSE requirements of the course.

Jenny meets the conditions of her offer and turns up to the college to enrol. During enrolment, the enrolment advisor does not ask if she has an impairment, as she hasn't ticked the box.

An opportunity for disclosure is not provided during induction, but one week into the course Jenny sees her personal tutor and says that she is worried about how she will cope with her course as she has dyslexia, but she does not want the other learners to know. He tells her that she has good GCSE results so she should be OK and to see how things go. Three weeks into the course, one of her subject teachers returns a piece of work and asks Jenny 'if she has considered that she might have dyslexia'. Jenny is very upset. The subject teacher claims she did not know that the learner had dyslexia and that Jenny should have told her at the beginning of the course.

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

# **Scenario 3**

Katie has enrolled on a course at her local college. She explains to a member of staff during enrolment that she has a visual impairment but would prefer that the other learners were not made aware of this. The member of staff enrols Katie and e-mails the lecturer about Katie's impairment and the need to produce course notes in font 16, but neglects to inform him about Katie's request for confidentiality. In the first class, this lecturer starts to hand out notes, and in front of all the other learners asks who Katie is, and then tells Katie that he has produced her notes in font 20 to make extra sure that she has no difficulty in reading them. Katie becomes visibly upset and leaves before the class finishes.

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

# **Scenario 4**

Ahmed enrols on a part-time evening class in pottery. On his enrolment form, he ticks the 'yes' box for the question 'do you have a disability, and he ticks the box for 'mental health difficulties'. The information, which is in small print at the bottom of the enrolment form, explains that his rights are covered by the Data Protection Act 1998. It further explains that the information will be held on the college database and will be passed on to the Learning and Skills Council for collection and statistical analysis in order to monitor college performance and improve the quality of future provision. He is not sure what this means or who the Learning and Skills Council are, but he is happy to sign the form. He does not want his lecturer or the other learners on his course knowing about his mental health difficulty, but does not have an opportunity to say to anyone that he wants this information to remain confidential. No one tells him that college staff will have access to this information.

Four weeks after the course starts, a member of the teaching staff talks to Ahmed and says, 'I didn't realise that you had mental health difficulties until I was on my computer and looked at the college data base for information on the group. How are you?'

# Workshop Activity – ACL

### Disclosure, passing on information and confidentiality

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

## Scenario 1

Bob is keen to study French at an evening class run by his local adult education college. He has a medical condition that means that at times he gets very tired. He feels that in general he will be able to manage in the two- hour sessions, but is worried that he might have to miss some classes and also that there may be times when he cannot stay in the class for the whole two hours and might need to have a short break.

He hands in his enrolment form to the reception staff and tries to raise the issue of his condition. However, the member of staff is very busy and says her job is just to take in the forms, and any individual needs must be discussed with the class tutor.

Bob goes along to his first class. The tutor gets straight onto the business of teaching French and at the end she leaves very quickly. Bob has no opportunity to discuss things with her in private.

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

# **Scenario 2**

Jenny has been formally diagnosed with dyslexia while at secondary school, and receives considerable support that allows her to achieve reasonably well in her GCSEs. She leaves school to work in a local bank and decides to enrol on an evening course provided at a local school. She does not tick the 'do you have a disability' tick box on the enrolment form, partly because she is extremely embarrassed by her condition and partly because she is not sure if dyslexia is a 'disability' as such. At enrolment, she is not asked if she has any additional support requirements or if she has a disability.

One week into the course Jenny sees a member of staff at reception and says that she is worried about how she will cope with her course as she has dyslexia, but she does not want the other learners to know. He tells her that she has good GCSE results so she should be OK and to see how things go. Three weeks into the course, her tutor returns a piece of work and asks her ifs she has considered that she might have dyslexia. The learner is very upset and makes a complaint. The tutor claims she did not know that the learner had a disability and that the learner should have told her at the beginning of the course.

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

# **Scenario 3**

Katie has enrolled on a course at a local community school. She explains to a member of staff during enrolment that she has a visual impairment but would prefer that the other learners were not made aware of this. The member of staff enrols Katie and emails the tutor about Katie's impairment and the need to produce course notes in font 16, but neglects to inform him about Katie's request for confidentiality. In the first class, the tutor starts to hand out notes, and in front of all the other learners asks who Katie is, and then tells Katie that he has produced her notes in font 20 to make extra sure that she has no difficulty in reading them. Katie becomes visibly upset and leaves before the class finishes.

For the scenario below, discuss the issues that are raised and the short and long-term responses you would need to consider to address these issues. Consider the issues that are particularly relevant to your organisation.

# **Scenario 4**

Ahmed enrols on a part-time evening class in pottery. On his enrolment form, he ticks the 'yes' box for the question 'do you have a disability, and he ticks the box for 'mental health difficulties'. The information, which is in small print at the bottom of the enrolment form, explains that his rights are covered by the Data Protection Act 1998. It further explains that the information will be held on a database and will be passed on to the Learning and Skills Council for collection and statistical analysis, in order to monitor performance and improve the quality of future provision. He is not sure what this means or who the Learning and Skills Council are, but he is happy to sign the form. He does not want his tutor or the other learners on his course knowing about his mental health difficulty, but does not have an opportunity to say to anyone that he wants this information to remain confidential. No one tells him that staff will have access to this information.

Four weeks after the course starts, a member of the teaching staff talks to Ahmed and says 'I didn't realise that you had mental health difficulties until I was on my computer and looked at the college data base for information on the group. How are you?'

# Summary of issues arising from scenarios

### Initial contact with any member of staff

A learner's first point of contact is often with a front line member of staff, for example reception staff, advice and guidance staff or a member of the administration team. Learners may well not be aware of the varied roles of different members of staff and some may want to discuss any requirements they may have with the first person they meet. Front line reception staff need to be aware of this and be sensitive to the fact that learners may need to pass on personal information to them. They need to listen carefully to the information the learner is giving them, check that they have permission to pass this information on, according to the organisation's procedures, and pass on information to relevant staff.

#### At interview or initial meeting with tutor

Individual learners may wish to discuss issues relating to their impairment with their tutor. It might be that learners do not declare an impairment on the initial application or enrolment form. They might be afraid that declaration at this stage might jeopardise their chances of a place. The tutor who first has contact with them will need to ensure that they give individual learners the opportunity to discuss any support requirements in confidence. They should then, with the learner's consent, ensure that this information is passed on to a relevant member of staff who can discuss support options with the learner, to ensure that requirements are met and appropriate support is put in place.

The tutor who has first contact may be a personal tutor for a full- time course, or the subject tutor if the course is part time. The member of staff may be part -time and may well be rushing from one class to another. However, it is important to ensure that all tutors are aware that learners need to have a time when they can discuss any support requirements they may have in a confidential setting. This is true for both full-time and part-time courses.

#### **Ownership**

It may be too easy for staff to perceive this as someone else's responsibility rather than their own. It is important that all staff recognise their role and responsibility in responding sensitively and responsively to learners with disabilities and learning difficulties.

### 'Unseen' impairments

It is easy to make the assumption that a learner does not have an impairment if it is not visible to everyone. However, a number of learners have 'unseen' impairments and it is important that all staff appreciate this.

#### **Communication and support**

Prospectuses, websites and any other marketing materials (for example course leaflets) should have clear and welcoming statements about the support that can be offered to any learner with a disability or learning difficulty. This should be accompanied by the name and contact details of the member of staff who co-ordinates support. It should include details of how a prospective learner can receive a copy of the organisation's Disability Statement. You might want to use this opportunity to draw peoples' attention to the marketing information and Disability Statement in use in your organisation.

Learners and prospective learners do not receive information solely from written marketing materials. They also gain it from the whole ethos and ambience of an organisation. It is perhaps useful to explore the extent to which you feel your organisation gives positive messages about disabled people, which will make a learner feel more confident in disclosing any support requirements. Some of these signals might be overt (for example, having Braille signs in lifts, etc.). Others are less overt but equally important and can be apparent in the way in which all staff approach and welcome the full range of learners. Inappropriate remarks, even if flippantly made or made with the best of intentions, show a lack of consideration of the impact that words can have on individuals. Very often, the discrimination that people face is not the result of an impairment or medical condition but rather the result of social, environmental or attitudinal barriers that people face, none the less powerful for being unintentional.

#### **Application and enrolment forms**

These need to provide an opportunity for learners to disclose. This is an opportunity for you to talk about the questions you use on these forms, highlighting the support options and the benefits of disclosing an impairment.

#### What happens to this information?

If a learner discloses a support requirement on an application or enrolment form, exactly what is done with this information will vary from one organisation to another, and this may be an opportunity for you to talk about your processes. What is important is that this information acts as a trigger for follow-up support, and everyone is clear on the process. While it is important that everyone in an organisation accepts ownership of responsibility, all organisations should have a member of staff who coordinates support for disabled learners.

An organisation will normally have arrangements in place to protect the security of data on a Management Information System (MIS). However, your organisation may have purchased software to help staff access course and learner information from a central MIS. Software that interfaces with a database and which allows staff access to the data, may not have limited access rights in place. This could mean that information on a learner, including information about an impairment, can easily be accessed by teaching staff. If this is the case, you must have a mechanism in place for explaining to a learner what happens to the information, who can see it, what it is used for, and a mechanism for obtaining a learner's consent. You should also have a mechanism in place for a learner who does not consent to this. The best solution is to ensure that information about a person's impairment that is stored on a college management information system cannot be accessed by staff.

The emphasis here should not only be about ensuring compliance with the Data Protection Act 1998 and the Disability Discrimination Act Part 4, but also about having a transparent and clear process so that a learner understands and feels 'in control' of the information they disclose.

#### Agreeing adjustments, respecting confidentiality

In order for attention not to be drawn to Katie's impairment, the member of staff who enrolled Katie should have clearly established how adjustments might be made that would be consistent with her request for confidentiality. It might have been appropriate to produce the notes in large font in advance of the class, for example, so that Katie can look at them before the lesson but would not have to be seen reading them in front of the other learners. Or Katie might have been happy to have had the enlarged font version (not font 20) given out in class, provided attention wasn't drawn to the fact that she had a set of notes in a different format. What seems to be missing is a clear discussion with Katie on what adjustments could be made and how those adjustments might best be made to ensure Katie's request for confidentiality is preserved.

## **Confidentiality and consent**

You need to have a clear mechanism in place in order to obtain a learner's consent to pass information about their impairment and support requirements on to other staff. It is essential to check with learners that they are clear on exactly what happens to the information they disclose and who will have access to it, both inside and outside the organisation. A learner may be happy for certain information to be passed on to others and the process of obtaining consent provides an opportunity for discussion in a confidential setting. It is important to appreciate that a learner has the right to confidentiality, even if he or she does not specifically request it. Consent cannot be inferred by silence. You may wish to use this opportunity to discuss your organisation's consent processes and documentation.

### Use of e-mail

E-mail may not be an appropriate way to pass on information about a person's impairment, unless they have specifically given consent to this method of communication, as e-mail is an open (ie non-secure) means of communication.

# **Appendix B**

Skeleton disclosure and confidentiality policy (taken and adapted from Maudslay and Rose (2003), Disclosure, confidentiality and passing on information, Appendix B pp35–38)

A skeleton disclosure and confidentiality policy is provided below and may assist you in drawing up appropriate documentation for your organisation. Policies are essential to ensure that all staff know what should happen in the event of disclosure, and their role in making it happen. You may decide that some of the information suggested below fits better into a procedure. There are no clear lines which divide the information that goes into a policy and the information that goes into a procedure and individual organisations will need to make their own decisions as to what is included in each document.

## Skeleton disclosure & confidentiality policy (disability)

#### **Policy statement**

This section should contain the aims and values of the organisation in encouraging students to disclose an impairment, making reasonable adjustments to meet requirements, and respecting the rights of a learner to confidentiality. For example, this section could include the organisation's ethos in terms of a welcoming atmosphere, a climate of trust, visible signs that diversity is valued, and recognition that meaningful consent is required before information is passed to others.

It might also be useful to acknowledge the responsibility of the organisation to make adjustments to meet the legal rights of disabled learners to education and inclusion. It might also be useful to explain the social model of disability and highlight the intention of the organisation to move towards it.

### Information and communication

This section could include information on, for example:

- marketing and publicity materials, in a variety of formats, that encourage disclosure, communicate the support that is available, and how support might be accessed
- information on application and enrolment forms that encourage a student to disclose
- information in staff handbooks

- information in student handbooks, diaries, student charter, etc
- prompts at interview that encourage disclosure
- how information is passed on from the point of disclosure
- how the organisation ensures ongoing opportunities for disclosure particularly before trips, visits, work experience, examinations, etc
- how you communicate with external referring agencies
- processes to review requests for confidentiality
- how the organisation provides opportunities for disclosure in confidential settings.

#### **Roles and responsibilities**

This section could include information on:

- recognition that all staff may be involved in the process of disclosure and will need to respond in appropriate ways
- roles and responsibilities of admissions staff during the application and enrolment process
- roles and responsibilities of marketing managers
- roles and responsibilities of tutors, eg during induction, before events such as trips, exams, etc
- roles and responsibilities of examination officers
- roles and responsibilities of staff responsible for work placements, coordinating work experience, etc
- roles and responsibilities of learning support coordinators or a named coordinator, for example in terms of the interviewing process, assessing requirements and identifying appropriate adjustments, communication with relevant staff, obtaining and using feedback from students, etc
- roles and responsibilities of front line staff and other support staff
- roles and responsibilities of teaching staff and support staff such as those in the learning resource centre, in terms of their role when a student discloses, and in receiving and acting on information from the learning support coordinator on the adjustments that are to be made
- roles and responsibilities of MIS staff.

#### Staff development

This section could include information on:

- what staff development is planned to implement the policy and procedure
- what staff development is planned for ongoing development, for example induction for new staff.

## Monitoring and evaluation

This section could include information on:

- how the organisation will monitor practice
- who will report to whom
- how monitoring information will be published, and to whom
- how monitoring information will be used to evaluate and improve practice
- how learners will be involved in the monitoring and evaluation process
- how information will feed into existing systems such as quality reviews, self-assessment reports and development plans.

#### Links with other policies

This section could include information on, for example, how this policy links with other policies and procedures, such as:

- disability equality policy
- inclusive learning policy
- equal opportunities policy
- admissions policy
- marketing policy
- health and safety policy
- data protection policy
- bullying and harassment policy
- Freedom of Information Act policy and publication.

The aim here is to ensure a coherent framework of policies and procedures rather than isolated policies and procedures that have little bearing on one another.

## Review date and responsibility

This section should identify who is responsible for reviewing the policy and by what date the review will take place.

This publication results from the Learning and Skills Development Agency's strategic programme of research and development funded by the Learning and Skills Council, the organisation that exists to make England better skilled and more competitive.

For further information about the Learning and Skills Council visit www.LSC.gov.uk







ISBN 184572349X