

**‘Be open to
the different
differences
that difference
makes.’**

Dr Tom Shakespeare

***[The disability teaching] really
opened my mind, it let me step
out of my box and look at things
differently.***

Healthcare student



Authors

Dr Margaret Byron

Project Director, Partners in Practice and Senior Lecturer in Disability
University of Bristol

Caro Howell

Project Co-Ordinator, Partners in Practice
University of Bristol

Professor Paul Bradley

Director of Clinical Studies
Peninsula Medical School

Dr Shekar Bheenuck

Principal Lecturer and Director of Student Affairs
Faculty of Health and Social Care
University of the West of England, Bristol

Claire Wickham

Director, Centre for Access and Communication Studies
University of Bristol

Tillie Curran

Senior Lecturer
Faculty of Health and Social Care
University of the West of England, Bristol

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To request a copy, please contact Claire Wickham,
Claire.Wickham@bristol.ac.uk

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Forewords

Running through Tomorrow's Doctors, the GMC guidance on undergraduate medical education, are the needs and expectations of disabled patients.

The GMC does not attempt to impose a national curriculum on medical schools. But that does not mean that medical schools should work in isolation.

This framework is a model of how good practice should be shared. It recognises that medical schools have sometimes struggled in their disability equality training and involving disabled people.

Aware of the pitfalls, the framework includes a strategy for ensuring that disability equality training gets the priority it needs, guidance on involving disabled people as curriculum planners and tutors, and an inventory of successful learning activities.

As good practice is shared, so the lessons can be considered and tomorrow's doctors will be better equipped to relate to all their patients as people, at the centre of the medical attention they need.

A handwritten signature in black ink, reading "Graeme Catto." The signature is written in a cursive style with a large initial 'G' and a long horizontal stroke at the end.

Sir Graeme Catto
President – General Medical Council

It's an honour to introduce this book. Partners in Practice has been an exemplary and innovative project which places Bristol at the forefront of medical education, and Margaret Byron and her team are to be congratulated and emulated. Visiting Bristol at the outset of their work, I was thrilled by the enthusiasm and dynamism of their approach to placing disability equality at the heart of medical education.

Since the 1970s, disabled people have issued a challenge. Society must accept its own responsibility for disabling people with impairment, and remove the barriers and prejudices which make the lives of disabled people unnecessarily difficult. In other words, disability must be de-medicalised. This agenda has prompted major changes in our streets and buildings, in our services and in the imagery which surrounds us.

Medicine too has changes to make. Understanding that disability is as much to do with discrimination as it is to do with bodily pathologies involves doctors in relinquishing some control, and seeing disabled people not as invalids, but as citizens. Disabled people do not necessarily want to be cured - they want to be respected, and they want to be healthy, on their own terms. The way to achieve this change of mindset is to listen to disabled people themselves, and to raise the awareness of healthcare students to better ways of working.

My late father was a doctor and a disabled person. He inspired many other disabled people to follow his path into the caring professions, challenged his colleagues to rethink their attitudes, and won the respect of his patients because they saw him as approachable. Understanding that professionals themselves can be disabled people – and indeed that all carers also need care - is part of what is necessary to break down barriers between experts and lay people.

Disabled people will always need doctors and nurses. Medicine has enabled many impaired people to survive and thrive, where in past generations they would have struggled and died. But good medicine knows its limitations. Appropriate interventions - rather than paternalism, or medicalisation, or normalising correction - are based on appreciation of difference, and true partnership between professionals, disabled people, and their families. This book shows the way.

A handwritten signature in black ink that reads "tomshakespeare". The signature is written in a cursive, lowercase style.

Dr Tom Shakespeare

Principal Research Associate, University of Newcastle



Key Findings for:

Higher Education Institutions

- Without champions at a senior level to endorse the credibility of the disability equality message, it is extremely difficult to effect real attitudinal change in either students or faculty.
- Do not ignore the impact of disability discrimination legislation on the future careers of your students, or it will catch up with you and them.

Healthcare Curriculum Developers

- Disability is integral to the Diversity agenda, not an add-on.
- Disability education should have the social model as a starting point, however, learning is most successful when students focus on practical ways to recognise and remove barriers.

Teachers

- Working with disabled tutors has a powerful impact on student learning.
- Disabled people and healthcare students believe assessment is critical, however existing tools are inadequate.
- Assessment is successful when it is learner-centred and located within their professional practice.

Who is this document for?

As a document for action, this framework is aimed at professionals delivering healthcare education – curriculum planners, module leaders, lecturers and assessors of pre- and post-qualification healthcare training. Consequently, the academic research that underpins this document is predominantly confined to the bibliography so that the framework can focus on practical issues of planning and delivery. Although the PiP project was concerned with the training of doctors, nurses and allied health professionals, it will also be a useful tool for those working in social care, training frontline NHS staff and in other areas where there is a professional-client relationship.

How to use this document

This document provides a positive framework and is a practical tool for delivering disability equality in health and social care curricula. We've tried to make this document as user-friendly, practical and useful as possible, dividing the document into relevant sections relating to curriculum design and delivery. It may be appropriate for you to go to the section that's most relevant to your area of work, but before you do, can we recommend you try one of the quick self-assessment tools on page 20.

Language and Terminology

The language of disability can be confusing. It is also continually changing, reflecting developments in legislation, our understanding of the complex issues, academic thinking etc. For the sake of clarity, within this document we are using the language of the social model with the following definitions.

Impairment refers to a medical condition or malfunction.

Disability refers to the restrictions caused by society through discrimination, ignorance or prejudice.

Disability Equality Teaching (DET) is teaching based on the social model of disability (see page 67 for a definition) with disabled people integral to the content and philosophy of the curriculum.

All quotations are verbatim.



Background

Barriers to health services are intolerable for any section of society but particularly so for groups known to be at high risk of premature death and ill health... Although many positive changes are taking place in the health service and individuals and organisations are beginning explicitly to tackle institutionalised disability discrimination, the pace of change needs to change. Otherwise many disabled people could die before full equality is achieved.

(Disability Rights Commission, 2004)

Equality for disabled people in society at large and healthcare in particular is long overdue and far from achieved. However, at the start of the twenty first century the introduction of legislation such as the Human Rights Act, the Disability Discrimination Acts (DDA) 1995 and 2005 and the Special Educational Needs and Disability Act (SENDA) 2003, the establishment of the Disability Rights Commission (DRC) and the development of Government thinking (Improving the Life Chances of Disabled People 2005), provides us all with both the imperative and the opportunity to tackle disablism and put an end to discrimination. So it is against this background that our curriculum framework has been designed and it is intended to be a document for action.

3% of women with learning disabilities take up cervical screening compared with a general uptake of 85%. (Department of Health, 1997)

Profoundly deaf people are 4 times more likely than hearing people to be diagnosed as psychotic at some time in their lives. (Sign, 2004)

50% of people with a mental health condition report being let down by the health service, including physical symptoms not being believed.

(Read and Baker, 1996)

70% of GPs do not provide any accessible information.

(Disability Rights Commission, 2004)

The risk of people with learning disabilities dying before the age of 50 is 58 times greater than the population as a whole. (Hollins et al, 1998)

20% of people who reported being unfairly dismissed or forced to resign due to mental health conditions had been nurses, from other caring professions or NHS employees. (Read and Baker, 1996)

For professions that consider themselves founded on principles of caring and service, it is uncomfortable to have to acknowledge the reality that healthcare is endemically disablist. From professional training and recruitment through to patient access and treatment, disabled people face discrimination. Only recently have our professions begun to listen and show signs of changing. This is hugely positive because a disabled person's relationship to a healthcare worker is unique. For unlike any other member of society, a health professional's work explicitly sanctions an intimate relationship. Therefore, the discrimination experienced in a healthcare setting is likely to be more invasive than in the corner shop.

...relevance is only there because I hadn't seen a patient with asberger's [sic] before. The session had no other relevance to my education.

2nd yr healthcare student response to teaching on how to communicate with learning disabled people

Disability discrimination is a human rights issue and part of the wider Diversity agenda. Although in the past disability has been as something of an add on to the established diversity issues of sexuality, age, ethnicity and gender, in reality it is integral. Disabled people are also people of gender, race and sexual orientation and this complexity needs to be addressed in healthcare education. Moreover, we would argue that because impairment is something that can affect anyone at anytime in their lives, the additional elements of fear and embarrassment are present when considering impairment. This extra dimension is particularly pertinent for healthcare workers for whom the admission of illness is a known taboo.

So why is it that a caring profession that concerns itself with impairment should be so susceptible to disability discrimination? Firstly, the way that students are taught about impairment encourages and reinforces a disablist approach. Disabled people become defined by their impairments since they are never likely to be involved in teaching, other than as a passive participant illustrating their particular medical condition. By that we mean that deafness will be studied as a condition within the ear, nose and throat specialty, rather than a deaf person being encountered during treatment for a cardiac condition or a pregnancy. Deafness therefore becomes pathologised and only of importance to certain specialisations, rather than seen as an important aspect of communication and therefore essential learning for all healthcare practitioners.

Thought this was a bit obvious. Disability can happen to you. Yep, I know.

2nd yr healthcare student

Secondly, there is enormous resistance within the profession, teaching faculties and the student body to acknowledge disability discrimination exists. A frequent student response to disability equality teaching is that it's just common sense and they know it already.

Introduction to Partners in Practice (PiP)

The Background to The Project

The University of Bristol has delivered disability equality teaching to undergraduate medical students for twelve years. In this time the teaching has grown organically in size and complexity, gathering institutional support and finding ways to overcome financial and philosophical obstacles.

Initially, teaching consisted of a three-day course in the students' fifth year run by a small steering group of health professionals and disabled people. A few years later disability became recognised as a vertical theme, and connections were made with other courses where disability teaching could feature. In order to map what teaching already existed an audit was undertaken within the Faculty of Medicine in 1988. Forty-eight course organisers were approached and their replies revealed that disability teaching was patchy, with disability notably absent from subjects where one would have expected it to be prominent, such as neurology.

Alongside the audit, a consultation was undertaken with disabled people and clinical teaching staff at Bristol to reach consensus on what Bristol's disability teaching content should be (Wells et al, 2002). The results showed that attitudinal issues ranked most highly with disabled people and a table of essential and desirable teaching content was produced.

WHERE NEXT?



Civil Rights



Equality



Awareness



The Law

These findings were then incorporated into a second audit in 1999 that included an additional question that asked; 'What does the term disability mean within the context of your unit of teaching?'

The second set of audit results revealed many more areas where disability featured within the curriculum. We concluded that this was the result of either the table of content alerting people to what was meant by disability teaching and/or that the first audit had raised awareness of disability amongst teaching organisers generally. However, the 1999 audit also revealed a very wide range of definitions of disability, making it clear that the issue was poorly understood.

Another outcome of the consensus exercise was to identify those disabled people keen to get involved in disability teaching at Bristol. So from 1998 onwards, disabled people became increasingly involved in devising, delivering and evaluating the curriculum that also became based on the social model of disability. Bristol's course has continued to evolve and is currently a four-day examinable course delivered in Year 2. Students have an OSCE (Objective Structured Clinical Examination) around hearing impairment where both the 'patient' and the examiner are hearing aid users and lipread. Various links have also been made with other teachers at different points in the students' training. However, the specific teaching block has always been kept deliberately separate to encourage students to view the course as applicable to their whole practice, rather than an impairment-based specialty.

32% of doctors judge a patient's "usefulness to society" when considering treatment.

(Disability Rights Commission, 2004)

Partners in Practice (PiP)

In 2003 the University of Bristol teamed up with the Peninsula Medical School and the Faculty of Health and Social Care at the University of the West of England, Bristol to form PiP. Our aim was to develop a curriculum framework that would work across both medical, nursing and allied health teaching using a range of delivery methods, including lecture based and Enquiry/Problem Based Learning (E/PBL) and different curriculum structures.

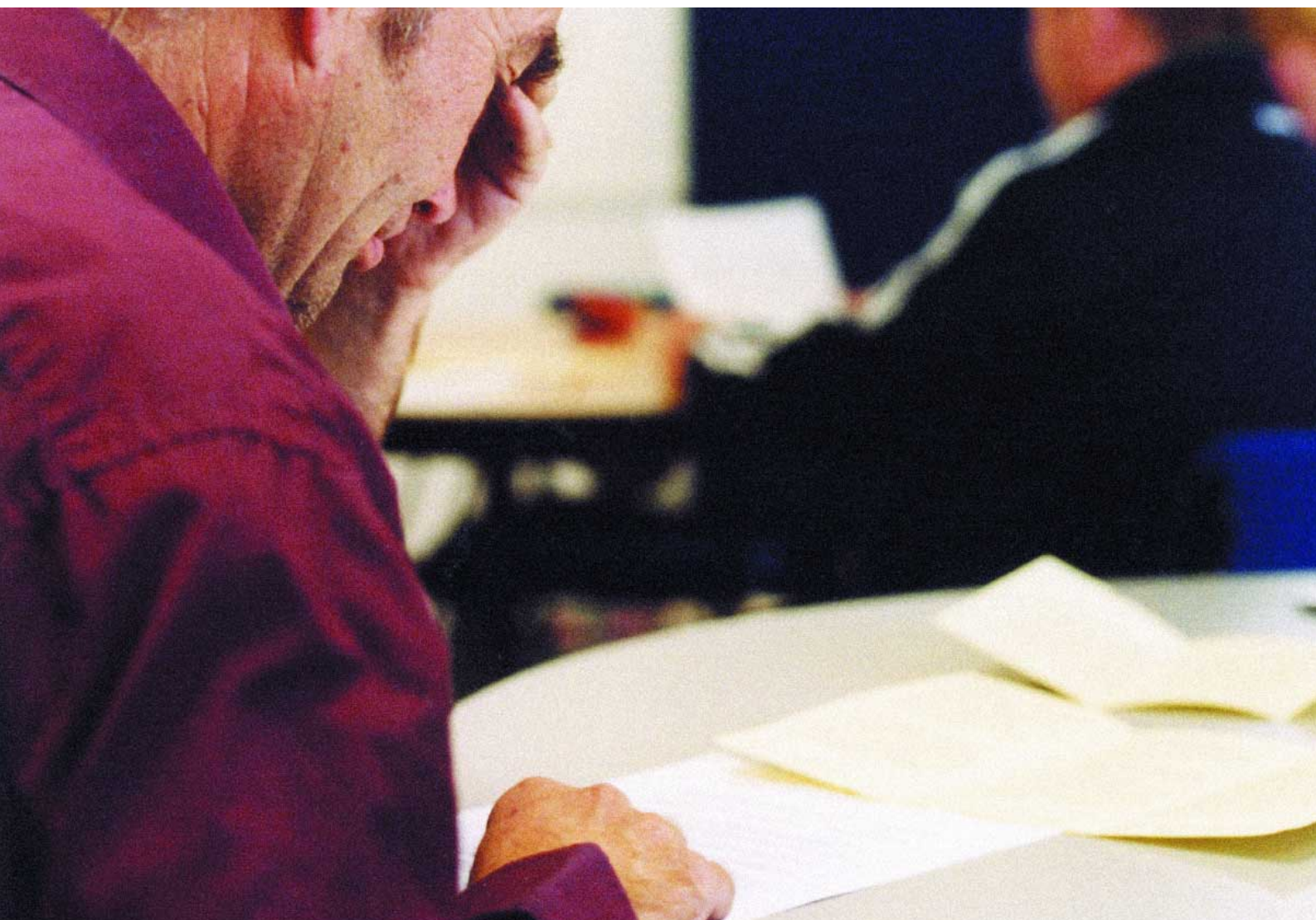
The Delphi Consultation

The Delphi consultation grew out of an initial 'Workshop for Change' attended by over eighty disabled people, representatives from disability organisations, health professionals and health educators. Their deliberations produced 12 categories/overarching themes of disability knowledge that health professionals needed to possess (see page 60). These categories were subsequently elaborated and focussed by workshop participants enabling the 12 categories to be broken down into smaller, more specific parts that we called 'descriptors'. These descriptors later became the learning outcomes.

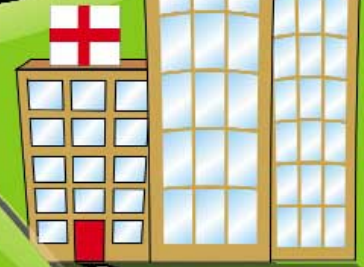
The final consultation document required every person to rank each of the 39 descriptors in terms of importance from 0–9 (9 being essential). They were also asked to rank the 12 categories from 1 to 12 (1 being the most important).

The Delphi consultation involved over 160 people – service users, educators, health professionals and academics – of whom 45% declared themselves to be disabled. To ensure that the process was inclusive, the questionnaire was available in a number of formats and could be completed by post, online or by phone. In addition, a workshop format was devised so that British Sign Language users and adults with learning disabilities for whom the questionnaire format was inappropriate could also participate (see the Path to Inclusion, page 16, for an example of material used with adults with learning disabilities).

Our original Delphi questionnaire can be viewed at www.bristol.ac.uk/pip/form.htm



The Path to Inclusion



Importance



5

All healthcare professionals should know about the various kinds of equipment and organisations that can help disabled people.

6

All healthcare professionals should know that society disables people, not their health condition.

8

All healthcare professionals should be able to communicate with a disabled person using any method they prefer.

All healthcare professionals should know how to involve carers or personal assistants in appropriate ways.

All healthcare professionals should understand the difficulties disabled people have getting health care and why this matters.

All healthcare professionals should know that people who are not disabled often have false ideas about disabled people.

All healthcare professionals should think about how they work with disabled people and learn to recognise and correct their mistakes.

9

All healthcare professionals should know about the Disability Discrimination Act and how it should affect the way they work

All healthcare professionals should listen to a disabled person's wishes about their treatment.

All healthcare professionals should realise that words are very important and powerful. They can affect how people think about disabled people and can hurt their feelings.

The 15 Essential Disability Equality Learning Outcomes

- 1 An understanding that disabled people with long-term conditions are often experts on their medical problems and lifestyle issues**
- 2 A recognition that different disabled people have different needs, identities and preferences**
- 3 A recognition that not all problems have a medical solution**
- 4 A recognition of the danger of excluding other diagnoses based on preconceptions about people with an impairment**
- 5 An ability to see a disabled person as capable of making rational life decisions**
- 6 Demonstrate an awareness of the communication needs of people with hearing, speech, visual, or learning impairments with real world experience to gain practice and confidence**
- 7 Demonstrate practice that values diversity and uses an equality based approach to healthcare and its outcomes**
- 8 Challenge the use of discriminatory language and advocate non-discriminatory language within their profession**
- 9 Remove barriers to disabled people's equal access to health services**
- 10 Recognise the rights of disabled staff members**
- 11 Recognise that disabled people's particular health needs may not be related to their impairments**
- 12 Practise equal opportunities in employment**
- 13 Recognise that people with 'invisible impairments' often have their access requirements overlooked**
- 14 Not letting carers or personal assistants speak for autonomous disabled people**
- 15 Demonstrate the ability to critically reflect on their practice and the practice of others**

The conclusions reached by the Delphi consultation backed up the findings of Bristol's earlier consultation. Of the top 15 ranked learning outcomes, the vast majority are around personal knowledge (attitudes) which students need before they can learn the propositional knowledge (knowledge) and demonstrate the process knowledge (skills) (Eraut, 1994). Furthermore, the rankings given in workshops by people with learning disabilities were almost identical to those arrived at by the main body of the consultation. However, the rankings given by BSL users did show significant differences, reflecting the fact that issues of poor communication dominate Deaf people's concerns about accessing healthcare.

75% of GPs have no training in treating people with learning disabilities, but 90% believed learning disability makes diagnosis harder. (Mencap, 2004)

40% of visually impaired people stated that their GP was not fully aware of their needs, rising to 60% for other surgery staff. (Guide Dogs Association, 2004)

Disabled people are four times more likely than the general population to find dentist offices inaccessible or inadequate. Twice as many find their doctor's surgery inaccessible. (Leonard Cheshire, 2002)

A Snapshot of Current Disability Equality Teaching

The top 15 learning outcomes informed our pilot teaching. The top 9 categories/overarching themes were used as the basis of the pilot audit of healthcare education institutions.

In order to gain an idea of how undergraduate healthcare programs currently approach disability equality teaching, seven healthcare education institutions (3 nursing and allied health professions, 3 medical and 1 dental) were approached and asked to participate in a pilot questionnaire. The questionnaire aimed to identify approaches to the design and delivery of those parts of the curriculum that dealt with disability. Questions were asked about the format of teaching and learning, and approaches to assessment in relation to the main themes identified in the Delphi consultation (see page 60). The questionnaire highlighted the following key issues:

Disability equality teaching was delivered as a theme (2), both course and theme (3) or in another form (2). The format of teaching and learning ranged from small groups to didactic lectures and with all modes in between. This variety was also matched by assessment modes, which ranged from OSCE stations through to reflective writing.

Our pilot showed that in order to obtain a complete picture of disability equality teaching and learning a questionnaire must be completed by a number of individuals who have responsibilities across a number of components of the curriculum as a whole. So future questionnaires may need parts addressed to curriculum planners, course directors and organisers, assessment leads and others. One person may be able to address all these aspects, but it would seem that cross checking with other individuals with other responsibilities will validate the data and might also reveal unknown aspects of the curriculum.

As a result of the pilot, we have reworked the questionnaire in order to address these needs more clearly and explicitly (see page 78). This could form the first step to an institutional audit for those involved in disability equality teaching.

Pilot Questionnaire Findings

- **There is a lack of clarity and no shared understanding of disability equality**
- **Complex curricula structures make it difficult for one individual to know where all disability teaching occurs**
- **3 institutions did not have or did not know of aims, objectives or outcomes relating to disability equality teaching**
- **Only 1 institution formally assessed student learning**
- **None of the teaching faculty had received disability equality training**
- **2 institutions used the social model of disability to underpin their teaching, 2 used other models, 2 did not know, 1 did not answer**

Wondering how disability equality aware you are?

The PiP team has reviewed available online self-audits that healthcare teachers could use to test their own understanding about the social model and/or disability equality. Information about models of disability can be found at the link to the DEMOS project, although this tool does not provide much interaction:

www.selfdirection.org/dat/training?cmd=guest&p=%2Fcourse01%2Fwelcome.html

The Royal College of Nursing have a publication that is a guide and workbook focusing on models of disability, the DDA and SENDA. There are 11 activities but no feedback or model answers.

www.shef.ac.uk/~md1djw/HCP-disability/disabilityissues/papers/ddarcnbook.pdf

A short (20 minute) quiz that “tests knowledge of disability equality issues” can be found at www.webequality.org.uk/freequiz.asp

There is also further online disability equality training available at a cost of £20 for employed, non-disabled people and is free for disabled people. The link to register for this training is: www.webequality.org.uk/Faststart1.asp and modules include definitions and models, the DDA, barriers to inclusion and disability etiquette.

~~4~~ Are there

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consequences of
disabilities?

~~9~~ What are De
situation. How mig

~~10~~ How will the s
the child?

~~11~~ What are the

What Will Be The Benefit of Adopting This Framework?

It really opened my mind, it let me step out of my box and look at things differently.

Discussing and presenting our ideas really let us see how we can be better doctors to our patients and also be better colleagues to doctors with disabilities.

I feel more confident about the way I would communicate with people with a disability and this would undoubtedly improve my future practice.

Even though I didn't realise it, I had my own prejudices and those have now been challenged in a very positive way. I feel more knowledgeable on the subject.

I will not be afraid to ask and I will not make assumptions.

Healthcare students' comments after disability equality teaching

From December 2006 the amended Disability Discrimination act places a duty on all public bodies including hospitals, primary care trusts and universities to actively promote disability equality. This General Duty requires that public authorities promote equal opportunities for disabled people, eliminate discrimination and harassment, promote positive attitudes and encourage disabled people's participation in public life.

A central tenet of disability equality is that accessibility, equality and respect are what every citizen expects from their society, be they disabled or non-disabled. Fostering an ethos of disability equality is essential for compliance with legal requirements and for enhancing inclusive professional practices, including the valuing of disabled colleagues.

Making A Start

In an ideal world, the development of a curriculum for teaching disability equality would follow the various strategic and structural steps outlined overleaf. In reality programmes and action plans often develop organically. This is born out by the experience of both the University of Bristol when developing their Disability Matters course, and the PiP partners when embedding our findings into their existing teaching. However, we hope the following provides a useful outline to taking your plans forward.



Exemplar

Timeframe

A first cycle of curriculum development as outlined in the exemplar should take about 18 months.

Not all of the steps are compulsory and you will probably find that you have to alter the sequence of milestones in response to the realities of your particular context.

However, before you decide to skip a step, take a minute to consider the likely consequences of losing the benefits they each bring.

Secure senior level commitment. Diversity should already be on their agenda but if necessary, use the requirements of disability legislation - the DDA, SENDA and the Human Rights Act - to advance your case.

Form a Steering Group of educators, practitioners and disabled people who can represent the wider disability community, preferably experienced disability equality trainers.

Conduct an assessment of your whole curriculum to discover where disability teaching occurs, what it is and how it is assessed and/or examined.

All parties sign up to a mission/value statement that endorses partnership and a commitment to practice grounded in the social model of disability.

Take the 15 essential learning outcomes and integrate them into your curriculum/matrix along with an assessment schema.

Re-audit your curriculum to monitor progress and consistency.

Evaluate the effectiveness of teaching and student learning.

Why Senior Level Support? Theories of attitude change stress the importance of the message's source having 'credibility' – the higher the credibility of the source, the more likely people are to believe the message and for it to change their attitudes. If you are introducing new and potentially controversial curriculum content, you are more likely to persuade both staff and students of its merit if it is seen to have backing 'at the top'. Equally the 'likeability' of the messenger is important, especially if one is being asked to adopt an attitude one originally opposed. (Eagly and Chaiken, 1993).

Why a Steering Group? A small group of interested, enthusiastic and committed people can help give your teaching shape by determining aims and objectives, finding contributors and evaluating outcomes. By including disabled people you will be able to tap into a range of skills, gain insight into their particular perspectives and refresh your understanding of current debates within disability studies, legislation etc. This will inform your decisions and ensure that a range of voices and views are heard and reflected in your teaching, including those of marginalized groups such as people with learning disabilities and BSL users.

Why Self-Assessment? Assessing your institution's disability teaching will give you a sense of where you are starting from and it will provide the baseline for subsequent audits. There is confusion within healthcare education about the meaning of the term 'disability equality teaching' and the answers of your course leaders and curriculum heads will help you gauge their understanding of the issues. The process will also reveal contacts with whom you can build networks and make alliances.

Why Sign Up to the Social Model of Disability? (for definition see page 67) This will determine the success or failure of your curriculum. Signing up to the social model will involve accepting the need for a philosophical shift in both staff and students towards the treatment of disabled people.

Why re-audit? Once your framework is in place, you will need to ensure that the equality and social model message are both championed and consistent throughout the curriculum.

Evaluation In the first instance, evaluation must focus on the impact your teaching is having on your students. However, the ultimate evaluation of disability equality teaching is testing whether disabled people are getting better healthcare provision.

Recent research has revealed the paucity of high level evaluation of provider performance and patient outcomes. Instead, medical education research is dominated by assessment of trainee performance and satisfaction. This represents an important challenge to researchers in this field. (Prystowsky, 2001; Kirkpatrick, 1994)

Reviewing Your Institution's Current Disability Teaching and Awareness

Review of curriculum is an on-going and evolutionary process.

The reason for assessing your institution's disability teaching is to ensure that the equality and social model message are both championed and consistent throughout the curriculum. Our experience has shown that this is unlikely to be the case. Certainly, in the first instance, you will get as many definitions of disability and disability equality teaching as there are people asked, due to the great confusion that exists within healthcare education about the meaning of the terms (for definitions see page 9).

Rather than undertake an audit of your institution's teaching, you could provide course leaders and curriculum heads with a self-assessment tool. Not only is this less intimidating, it allows you to gauge people's understanding of the issues through their answers, thus giving you a starting point. In due course it will provide the baseline for a future audit cycle.

We have developed a self-assessment template that you might find a useful starting point (see page 78). You may wish to make adaptations or develop your own tool, however it is worth bearing in mind the need for questions to be extremely specific if they are to elicit the answers you are after and avoid adding to existing confusion.

Whether you run disability teaching and learning as a discreet course, as part of a combined modular programme or as a theme, it is recommended that there is somebody taking a lead for disability issues who can comment on any particular area they directly teach on or who oversees where disability occurs throughout the curriculum. This is the person with whom to start the process of institutional assessment. It is essential that they are in a position to influence curriculum development.

Moving Forward From Muddle

When your self-assessment forms are returned, it is likely that the results will be patchy, confused and conflicting. However, you will have some baseline data and contacts with whom you can build networks and make alliances.

At some point in the process you should select the key people who need disability equality training, in order that everyone shares a single understanding of what is meant by disability equality and the social model of disability. When organising the training, try if possible to have it tailored to the needs of health practitioners. In that way it can address issues such as Fitness to Practice, competencies and the physical contact inherent in healthcare and unique to the professions.

The Heart of the Matter

Planning your curriculum will involve your team agreeing and organising teaching content and deciding on educational strategies, delivery and assessment methods. All of this has to start with a theoretical underpinning rooted in the social model of disability and the success of your curriculum is dependent on everyone signing up to the model, understanding what it means and particularly how it differs from holistic medicine.

The Social Model of Disability

There are many models of disability. The social model has been criticized for being dominated by white male Euro-centric ideologies and the debate is ongoing. However, the most commonly cited dichotomy is social vs medical model. Put at its simplest, the medical model sees disability as a problem situated with the individual who needs curing and where this is not possible, managing by others who can help make their life as 'normal' as possible. The social model on the other hand situates the problem with society, which denies disabled people their human rights by abdicating its duty to remove the barriers that prevent them from participating on equal terms with non-disabled citizens.

While the term 'medical model' is meant to reflect the negative effects of medicalizing disability, it is easy for healthcare practitioners, educators and students to interpret it as placing the blame for disabled people's discrimination at their door.

Typical responses to disability equality teaching are that it is:

- common sense
- patronising
- rubbish
- political correctness gone mad

As young people who have committed their lives to the service of people with illness, we are unlikely to be insensitive and blind to individual needs of patients.

Very little to be learnt which was of any use. Some interest but no use.

I wish I had been learning real medicine.

This is subjective material going as fact. I don't agree that the origin of words such as 'handicap'... make them redundant within our language.

2nd year healthcare students

One significant aspect of healthcare education that inadvertently reinforces the medical model of disability is the fact that disabled people are rarely 'taught on' as patients except in relation to their impairment. Students often comment that disability equality training is unnecessary as they see disabled people all the time. However, what they do not experience is treating disabled people for conditions or complaints independent of their impairment. It is easy to see why it is quicker or simpler for clinicians to select patients who present no additional health or communication issues. Not only does this contribute to the marginalization of disabled people, it ill serves the students. Teaching and learning theory shows that learning is most effective when learners are stretched beyond their comfort zone (Vygotsky's "Zone of Proximal Development", cited in Jarvis et al, 2004).

Social Model and Holistic Medicine

In our experience many people confuse practicing holistic medicine with practicing healthcare within the social model of disability. The two are not mutually exclusive, in fact they should be practiced together. However, it is essential to realise that holistic practice does not preclude discriminating against disabled people. It is also important to acknowledge that adopting the social model in professional practice is going to be a challenge because healthcare training is medical model focused.

The easiest way to show the difference between holistic and social model medicine is by example:

A student presented a case study involving a man with morbid obesity and all the medical problems associated with that, such as lack of mobility, heart failure and weeping peripheral oedema. He outlined all the medications the man took, his home situation and the involvement of various members of the healthcare team including, dietician, occupational therapist, physiotherapist, social worker and hospital specialists. He listed the various aids and equipments the man had been given, though rarely used. Through discussion it was revealed that this man had become the centre of his small community. He provided a telephone directory service for locals and he had several visitors daily as he was a well-liked person with a keen sense of humour. He had a good relationship with his wife and he continued to make materials connected with his previous work from his armchair. The student concluded the presentation with the probability of the man dying within the following year and the despondency felt by the primary care team that they could do so little to help him. The student had done a very thorough job of looking at this man within the context of his whole life (holistically) and described the situation as desperate with no positive dynamic.

In fact, this man had his identity intact and his aspirations met by the fact that he had adapted his environment to suit him. He was aware of his prognosis to the extent that he wanted to and was determined to enjoy his life.

The healthcare team had done all the appropriate things to lessen his impairment and to challenge his apparent lack of expectations of better health. However, they had based their idea of his quality of life on their understanding of his medical condition and prognosis and not who he was as a person. Not all people can be as determined as this man and the role of health professionals is to provide expertise, information and support for people to find what they want as well as advise on the best treatment. Only then are they able to use their expertise and position to influence environmental change – the social model.

Using the social model as a starting point automatically involves greater mutuality between health professionals and patients.

Getting the Message Across

So how do you tackle these complex issues without alienating your colleagues and students? Typically, disability equality teaching begins with an explanation of the social model and stresses its primacy throughout. Yet our experience shows that regardless of how you nuance this approach, you will always alienate a significant and vocal proportion of your audience. However, an alternative delivery model was revealed by the PiP Delphi consultation. When ranking the overarching themes in order of importance, participants placed 'An understanding of the social model of disability' ninth out of twelve and below more practical issues of awareness of communication needs and challenging discriminatory language. Our experience has shown that focussing disability teaching on practical measures which can be adopted in professional practice and promote equality of treatment, whilst leaving discussion of the social model until the very end, will reduce cognitive dissonance dramatically.

Promoting the Social Model

- **avoid starting with direct attacks on the medical model**
- **use the term individual model instead of medical model**
- **focus on practical issues first before tackling disability theory**

The process of preparing staff for the introduction of disability equality teaching will include the development of a value statement. This will encapsulate the core priorities and can drive the intent and direction of planning. It can also bring together the views of all participants – disabled and non-disabled, health professionals and educators, service users and carers. Ideally, a champion or two at a high level of institutional authority and with credibility amongst colleagues should be involved in the whole process. At the very least they should sign up to the value statement once written and be actively involved in its circulation, helping to develop the critical mass amongst other professionals needed to take the process forward.

When it comes to disability teaching nuance is everything. Therefore, as the value statement is disseminated across the institution and its curricula, it is important to monitor that it is being interpreted accurately.

Designing Your Disability Teaching

At the heart of PiP has been consultation with disabled people, not simply as service users, but also as educators and health professionals. It is their first hand experience and expert knowledge of their impairment and/or obstacles to accessing healthcare that inform the project's learning outcomes and should inform any curriculum if disabled people's involvement is to avoid tokenism.

Our top 15 learning outcomes reflect the consensus reached by over 160 people. 45% of these described themselves as disabled; the data revealed the top 15 outcomes remained the same regardless of whether the participant declared as disabled or non-disabled. What did alter slightly was the priority assigned to each one, some of which was explained by age and gender. We feel confident in recommending our curriculum learning outcomes as the basis for any teaching and learning activities.

Disabled People as Curriculum Planners and Tutors

Disabled people are often experts in their impairment and have a unique insight into what it means to be a service user. This can be hugely valuable for our future health professionals as it has the real potential to bring about a change in understanding and practice.

Disabled people's involvement in curriculum planning and delivery needs to be active as this will ensure that teaching is through them, not about them.

Disabled people have a lot of contact with the medical profession; therefore, I think it is crucial for students to hear from empowered disabled people how they have been treated, and how they would like the system to be improved.

When attending disability training delivered by disabled people, health professionals are exposed to some of the ways disabled people deal with the barriers that they meet in all aspects of their lives.

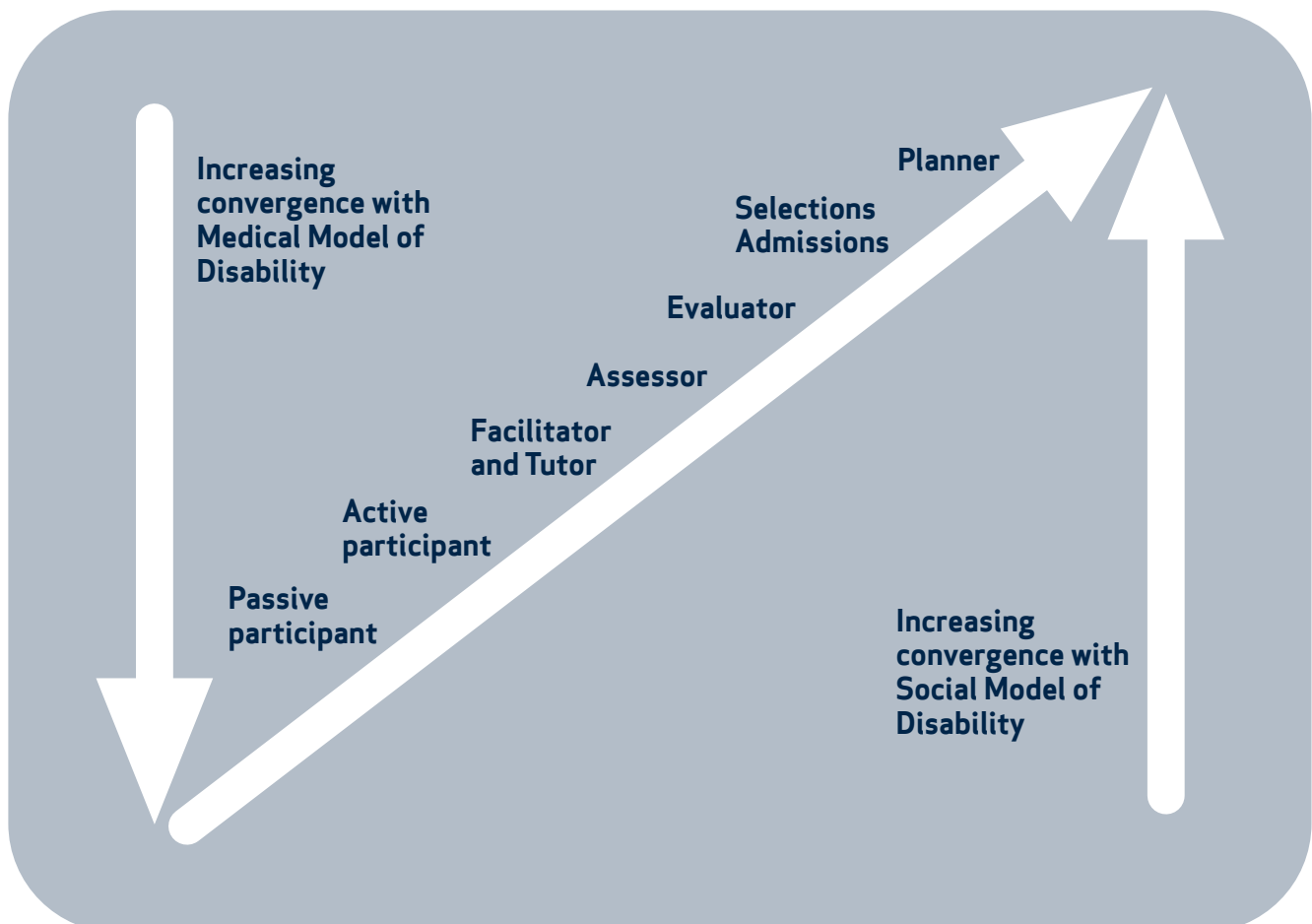
Disabled tutors

We were all surprised at [the disabled doctor's] capability to adapt and we were all slightly taken aback when he appeared in a wheelchair. He had a huge impact on all of us.

Using disabled tutors really gives weight to the material being taught. Showing just how capable they are breaks stereotypes and challenges opinions probably more than the teaching itself. Gives insight into their world and really shows how wrong our attitudes are.

Healthcare students

Figure 1. The continuum of service user involvement in healthcare education



It would not be unreasonable to assume that if a disabled person was working as an evaluator on a healthcare teaching programme, they must be working within a social model framework. However, this is not necessarily the case. At every level of participation it is possible for disabled people's involvement to be tokenistic. Outlined below are examples of each role indicating their convergence into the social model of disability (number of triangles equals strength of compliance).

Passive Participant

- ▲ The patient in a bed or in an out patient clinic. Their only involvement will be in answering the question 'Are you willing to be seen by students?'

Active Participant

- ▲▲ The Expert Patient: trained to teach on their own particular impairment. The focus is still on impairment rather than disability equality.'

Facilitator or Tutor

- ▲▲ The disabled person is asked to turn up, talk about their impairment and/or life experience and answer questions.
- ▲▲ The disabled person is involved in planning the session and its learning objectives, is introduced as the tutor and their feedback is acted upon.

Assessor

- ▲▲ The disabled person acts as a body with an impairment having had input into the process of the examination and the marking criteria .
- ▲▲ The disabled person acts as marker, having had input into the process of the examination and the marking criteria.

Evaluator

- ▲▲ The disabled person receives student feedback, gives feedback to course organiser/s and is involved in evaluating the course/module/theme and subsequent developments.

Selections and Admissions

- ▲ The disabled person is involved in a tokenistic way.
- ▲▲ The disabled person has an equal 'voting' presence in the selection process.

Curriculum Planner

- ▲ The disabled person is involved in a tokenistic way.
- ▲▲ The disabled person is involved in the ongoing development of limited aspects of the curriculum.
- ▲▲ The disabled person is involved in the ongoing development of all aspects of a curriculum including its philosophy.

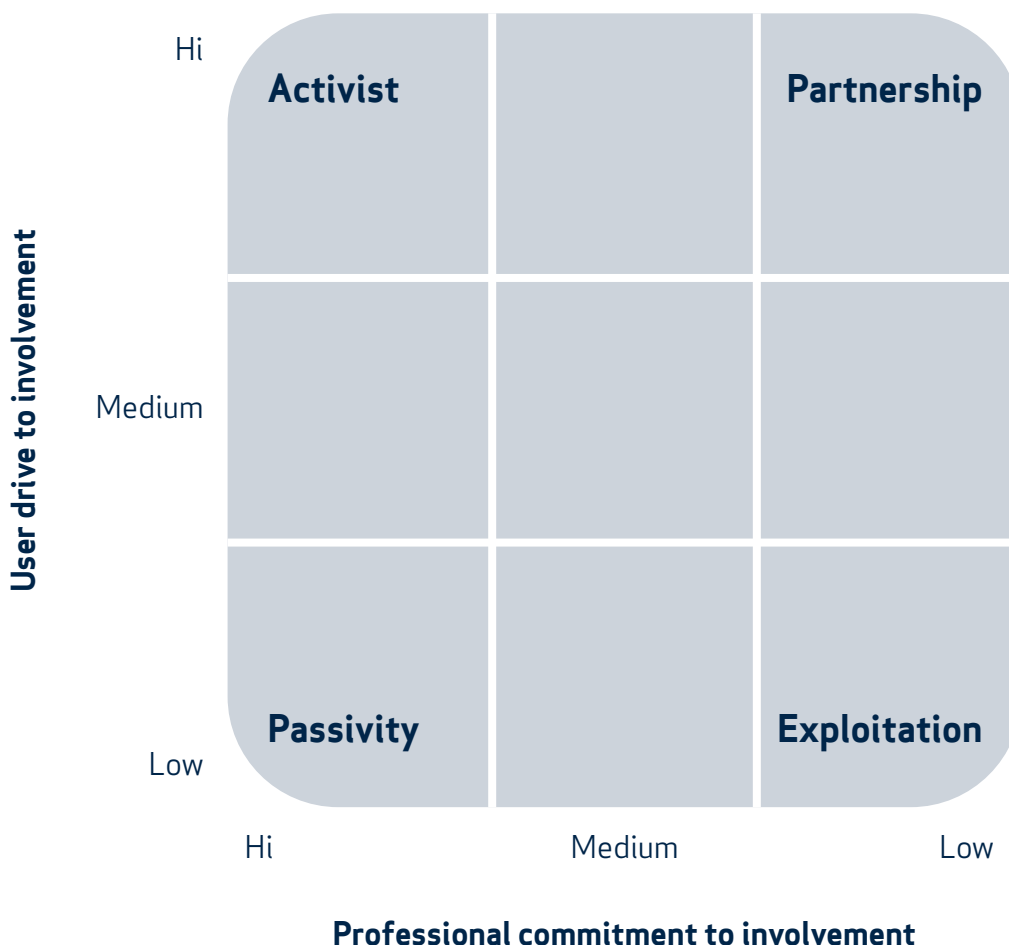
The introduction of disabled tutors may result in some teaching staff being anxious about roles and/or resistant to change. This can be managed if they can see the changes as:

- an opportunity arising from new legislation and changing societal views
- a benefit to the institution by reinvigorating and innovating existing learning structures and creating new educational experiences
- not displacing 'old' knowledge, rather the understanding associated with that knowledge is being developed so that it may be deepened and applied in more insightful and effective ways

The following matrix might help you envisage current practice prior to planning or changing existing disability equality teaching.

The matrix can be used to provide an institution with a visual snapshot of where the involvement of disabled people actually lies. It can then give the institution an illustration of the scale and direction of movement required to shift their current position towards the most desired sector (top right). Used as an animated graphic with a small coloured circle towards the left lower sector moving and growing as it approaches the upper right, can be a powerful metaphor for the commitment of the institution.

Figure 2. An analysis matrix of existing curriculum involvement



Professional Development for Existing Staff and Disabled Tutors

Ensuring a smooth transition to a new teaching environment includes recognising that there may be difficulties, both for existing staff having to adapt and disabled teaching staff who may have little or no experience of working within higher education.

A staff development programme that builds on their strengths and recognises their contribution to past learning will prevent them feeling demoralised or isolated from the change process. Involvement in the following will help develop a sense of ownership of the process:

- analysis of where teaching has been and why it is changing
- workshops to develop relationships with those disabled people who will be involved in the programme
- development of learning activities in partnership with disabled people
- development of processes for reviewing and monitoring quality

Depending on their experience, disabled people may need an introduction programme to assist them in developing an understanding of your curriculum and its specific needs, as well as training or other support to develop the confidence and competence to successfully participate in the programme whatever their level of involvement. This might involve:

- teaching-the-teacher
- mentoring
- observation
- peer appraisal of teaching
- a formal programme for developing educational qualifications

A superb opportunity to hear not only how to communicate with people who are visually impaired, but also what it was like to be visually impaired.

For me, a big issue is fear and embarrassment. I'm a nice person, with good intentions - as are most of us - but terrified of working with and making mistakes with disabled people.

I felt that communication issues [taught by] people with learning difficulties completely changed my view about how to view people with learning difficulties.

Healthcare students

Making Contact with Disabled People

There are a number of ways in which you can make contact with disabled people; each has benefits and drawbacks. Whichever route you choose, it is important to remember that every disabled person is unique in terms of their life experiences, impairment and attitude towards being disabled. Expecting an inexperienced or untrained disabled person to represent 'disabled people everywhere' is unrealistic when an individual may not even be experienced in representing others with similar impairments. There are two solutions to this problem:

- Involve a number of disabled people who can relate first hand experience of the issues involved in a wide range of impairments.
- Involve disabled people who are professional consultants on disability issues, particularly if they are experienced disability equality trainers.

These approaches will better enable undergraduate students to:

- understand the complexities of disability
- recognise their own misconceptions
- overcome fears or embarrassment related to specific impairments
- learn how to use a range of communication strategies

The first approach has the advantage of giving students contact with people who have a variety of access requirements, while the second should provide training that reinforces the social model of disability.

It is important to address and challenge dominant assumptions or anxieties about disability. For instance, only 4% of disabled people are wheelchair users, yet if you were to ask the average person what word or image they associate with disability, the chances are they will say “a wheelchair” (Byron et al, 2005). In reality, the needs of people with ‘hidden impairments’ such as deafness or chronic pain are often forgotten or overlooked, while people with learning disabilities, mental health service users and British Sign Language users are especially marginalised and discriminated against by society.

Recruitment

There are a number of different approaches you could use to recruit disabled people to your curriculum staff. Bearing in mind the need to spread your net wide, you could approach:

- local and national campaigning or charitable organisations
- voluntary and independent organisations
- self-help groups including via email newsletters
- local media and specialist disability press
- interested individuals who have approached you
- those identified by health professionals and/or colleagues as having an interest
- patient advisory groups and social services

In addition to local disability groups, there are disability coalitions and action groups such as People First or the British Council of Disabled People (BCODP). These groups have strong networks of disabled professionals including disability equality trainers as well as strong political agendas. Their politics may or may not be appropriate for the approach you are taking. One good source for disability consultants and experienced trainers is a public database of disability equality trainers at <http://www.cam.ac.uk/cambuniv/disability/trainingdb/>. If you are based in an HEI or FE College then your Disability Office staff may also know of suitable local trainers.

It's important that if people don't understand they should feel able to ask questions. Don't be afraid or embarrassed.

Disabled people are quite capable of expressing themselves. Sometimes they might need additional support keeping to time, ensuring all equipment is set up in advance, getting information in order or if the audience is very large it can make them nervous.

Tutors with learning disabilities

Payment

The involvement of disabled people in both planning and delivery must be seen to be an acknowledged professional and expert activity and suitably rewarded. Payments might include agreed university rates for visiting tutors. Equally payments might be made for planning meetings, consultancy and training.

Disabled people who receive benefit payments might jeopardise these if they earn more than a certain amount in a fixed time period. In these cases you may decide to reach a mutually agreeable method of acknowledging their valuable participation, or they may receive payment through a disability organisation with whom they are affiliated.

Other potential expenses include:

- travel expenses
- fees for support workers/Language Service Professionals
- communication aids e.g. Braille or audio transcripts, portable loop systems.

Self-employed disabled trainers or consultants may have their own Access to Work funding that will pay for their access requirements.

Points to Remember

- **Are your venues accessible for disabled tutors e.g. equipment, layout and facilities including toilets and parking?**
- **Do you have representation from a range of disabled people/groups?**
- **Do your disabled tutors have the appropriate experience and training?**
- **Do your disabled tutors need support in terms of briefing meetings, teaching preparation, delivery, evaluation and feedback e.g. BSL interpreters and information in alternative formats?**
- **Are traditional methods of tutor payment appropriate or do alternative arrangements need to be made?**
- **Are your goals for disabled tutor participation realistic?**
- **How will disabled tutors' feedback be obtained and their views acted upon?**



Curricular Content, Teaching Methods and Evaluation

The following teaching and learning activities are examples of possible ways to deliver specific learning outcomes from our essential top fifteen. We offer them as suggestions rather than rigid schemes of work in the knowledge that you will need to adapt them to meet your particular teaching requirements and context.

Many of the learning outcomes are engaged the moment students begin working with disabled tutors. Through observation and discussion with disabled tutors (who are present not as patients to be learned on but as tutors to be learnt from), students develop an understanding that:

- the majority of problems disabled people face do not have medical solutions
- discrimination and barriers have a greater negative impact on their lives than their impairment
- disabled people are autonomous individuals capable of making rational life decisions.

The following activities have all been successfully tested and evaluated with medical, nursing and allied health students. The criteria for evaluation were whether the various activities successfully delivered selected learning outcomes and whether activities would suit small and/or large group teaching situations. The majority of these activities work best in small groups due to the nature of the interaction between students and tutors. Many can be adapted to suit a lecture or large group format and inter-professional learning. Some tutors who require assistive equipment such as portable microphones might find large groups particularly problematic if there is to be discussion.

The 15 Essential Disability Equality Learning Outcomes

- 1 An understanding that disabled people with long-term conditions are often experts on their medical problems and lifestyle issues**
- 2 A recognition that different disabled people have different needs, identities and preferences**
- 3 A recognition that not all problems have a medical solution**
- 4 A recognition of the danger of excluding other diagnoses based on preconceptions about people with an impairment**
- 5 An ability to see a disabled person as capable of making rational life decisions**
- 6 Demonstrate an awareness of the communication needs of people with hearing, speech, visual, or learning impairments with real world experience to gain practice and confidence**
- 7 Demonstrate practice that values diversity and uses an equality based approach to healthcare and its outcomes**
- 8 Challenge the use of discriminatory language and advocate non-discriminatory language within their profession**
- 9 Remove barriers to disabled people's equal access to health services**
- 10 Recognise the rights of disabled staff members**
- 11 Recognise that disabled people's particular health needs may not be related to their impairments**
- 12 Practise equal opportunities in employment**
- 13 Recognise that people with 'invisible impairments' often have their access requirements overlooked**
- 14 Not letting carers or personal assistants speak for autonomous disabled people**
- 15 Demonstrate the ability to critically reflect on their practice and the practice of others**

Learning Activity	Outcome	Content
<p>A Learning Log</p>	<p>15</p>	<p>By keeping a learning log, students are able to see the development of their ideas, the change in their attitudes and the broadening of their knowledge of disability related issues. They also provide staff with an insight into those areas that still need to be addressed or revisited.</p>
<p>The Identity Exercise</p> <p>Choose and Reject Exercise</p>	<p>2, 3 & 5</p>	<p>Identity Exercise: students individually write down five or six factors that give them their sense of identity. In discussion with the tutor, students then consider which aspects of their identity they would refuse to give up and which they feel could not be changed even in the event of developing impairments.</p> <p>Choose and Reject: The tutor presents the students with four impairments e.g. blindness, learning disability, psychiatric illness and paraplegia and asks them to think about/write down which impairment they feel least able to cope with and why and which impairment they feel best able to cope with and why. Discussion arises from the fact that it is usual for at least one of the impairments to be equally chosen or rejected.</p>
<p>Images and Language</p>	<p>8</p>	<p>Students start the session by deconstructing representations of the female nude in art and advertising, in order to reveal the visual codes embedded in the images e.g. the assumed male gaze, the commodification of the female body and the removal of sexual autonomy. Students then analyse images of disabled people taken from charity posters to explore the negative attitudes encoded within them. Finally they study a range of images of disabled people from art, literature and popular culture to reveal the role of culture in reinforcing society's negative attitudes. Discussion of language emerges through the process of verbalising the attitudes embedded in the visual images.</p>

Learning Activity	Outcome	Content
<p>Ask the Elephant</p>	<p>1 & 10</p>	<p>The tutor facilitates discussion around issues raised by Amanda Kvalsvig's article taken from The Lancet (see page 59). Ms Kvalsvig is a deaf doctor and she succinctly and humorously illuminates a number of important issues around the need to acknowledge a disabled person's autonomy, individuality and level of expertise in their own condition. She also demonstrates the pitfalls of making assumptions about the needs and abilities of disabled people both as patients and as healthcare colleagues.</p>
<p>Scenario, Presentation and Write Up</p>	<p>5 & 14</p>	<p>Students are presented with a scenario – in our pilot a pregnant adult with learning disabilities is in a loving relationship but her mother is adamant she should have an abortion. Students are put into groups to research the topic before presenting their findings and conclusions.</p>
<p>Learned Helplessness</p>	<p>5 & 14</p>	<p>This lecture explores the issue of unhelpful help, where disabled people are treated as if they have lost the capacity to make rational decisions and professionals make life choices for them. The result is that disabled people lose confidence and learn to be helpless, reinforcing the original assumption. Students discuss ways in which health professionals can enable a disabled person to be self-determining by supporting their life choices (see pages 64 and 65).</p>
<p>History of Disability</p>	<p>15</p>	<p>A disabled tutor gives a lecture on the political, social and medical history of disabled people both in the UK and abroad.</p>
<p>Communicating with visually impaired people and D/deaf people</p>	<p>2, 6, 9 & 13</p>	<p>These communication sessions are all run by tutors with the relevant impairments. Tutors talk about their own experience of their impairment, barriers to accessing healthcare and how to remove them as well as methods for improving communication. Students experience many of these communication methods in action during the session. Students are encouraged to ask any questions they have regardless of whether they feel they might be naive or embarrassing.</p>

Learning Activity	Outcome	Content
<p>Communicating with people with learning disabilities</p>	<p>2, 6, 9 & 14</p>	<p>This session is led by people with learning disabilities. The tutors talk about their own experience of impairment, barriers to accessing healthcare and how to remove them as well as methods for improving communication. Students experience many of these communication methods in action during the session.</p>
<p>The Carer's Perspective</p>	<p>14</p>	<p>This session is led by carers and/or disabled people and outlines the functions of a carer and the differences between this role and that of a personal assistant (PA) or Language Service Professional. It is important that students understand what each role involves because of their different relationships to the disabled patient. This knowledge will impact on the student's working practice.</p>
<p>Disability and Ethics</p>	<p>1, 3, 5, 7 & 15</p>	<p>The disability and ethics topic discussed at Bristol is 'termination due to impairment'. The discussion is interwoven with excerpts from a Radio 4 programme about disability in which genetics and pre-natal testing is covered. Student discussion is facilitated by a disabled person and an ethicist versed in current medical and legal practice. The aim of this session is not to discuss the rights and wrongs of termination but rather the responsibility of the health professional in a situation of this nature.</p>
<p>Experiences of Disability</p>	<p>1, 3, 5</p>	<p>The session is facilitated by a disabled person. In small groups, students are encouraged to share their experiences of disability with that of the tutor. The aim is for the students to gain valuable insights into the breadth of disability issues: the physical, organisational and attitudinal barriers disabled people face, the practicalities of day to day life and the use of aids e.g. assistance dogs, equipment and PAs. The video 'Talk' produced by the Disability Rights Commission is used and provokes a great deal of discussion.</p>

Evaluation

The Identity Exercise and The Choose and Reject Exercise

These quick and simple exercises work particularly well at the very start of disability equality teaching. They enable students to confront, often for the first time, their preconceptions about disability. They enable students to see how their rational attitudes and decisions about impairment can be completely opposite to those held by their equally rational peers. This graphically illustrates the need to recognise that a disabled person's personal priorities will effect their decisions about treatment. These may not necessarily match those of their health team who are coming with their own attitudes to a particular impairment.

In addition to the main learning outcomes, this exercise also enables students to:

- focus on the complex network of factors that make up personal identity and how each individual will rank similar factors differently
- consider how, if at all, their sense of self would be affected by impairment
- make connections between the individuality of their desires and ambitions and those of their future disabled patients

The Choose and Reject exercise is adapted from an idea of Stephen Duckworth's from Disability Matters.

Student Feedback

I've never really thought that deeply about my own identity before.

It was mainly discussion of basic things but in a new way so that things 'clicked' like they haven't before. Doing my own identity profile was so useful, as I saw where I rank my own disabilities and illness and what is important in my identity, and so many other things were above them. This is important to realise as we look at patients through their illness when to them that's not the most important thing, that's very important to realise. Also having a disabled tutor really hammered home the fact that people are not their disability but so much more. I found this session very useful and feel it is a very good introduction to the topic of disability.

I knew everyone's identity was different and important, but the actual needs of each individual isn't something I have actually thought about.

Never to assume how a person feels a disability affects them. That focussing on someone's disability can result in inappropriate treatment because you fail to see the whole person and their needs.

Disabled Tutor's Feedback

The session needed the group members to be forthcoming with personal aspects about themselves for it to work. I think that importantly it showed that it wasn't always easy to surrender personal information about themselves. It's all too easy to assume that disabled people don't mind talking about their problems / issues and I think that this session could show, if handled correctly, that an element of trust is required before someone might share personal information. It highlighted the privilege that healthcare workers have and a sensitive approach when relating to people about their issues of concern should show appreciation of this privilege.

Images and Language

Healthcare students and practitioners are often resistant to suggestions that their language is discriminatory and should be changed. This activity successfully tackles the issues by using a lateral approach, tackling the subject from a discipline traditionally thought of as entirely separate from healthcare. Students explore how society's negative attitudes towards disability are generated and enforced by culture. Different forms of cultural production – art, the media, literature, advertising – may reinforce discriminatory attitudes in the overt and unconscious vocabulary they use. In this way students can see how their attitudes are shaped by their socialisation rather than being a conscious, individual choice.

The session has been run in both a small group and lecture situation. Small groups allow students to work in pairs analysing the charity posters and present back to the group. A lecture format requires that the tutor lead discussion from the front and prompt comment from students. However, both delivery methods produced similarly positive results.

Student Feedback

This has provided me with a lasting image of how disability is portrayed by the media and why we possibly all have some level of stereotyping / embarrassment / discrimination when it comes to disability issues.

A unique way of seeing how attitudes are developed.

Analysing the posters was a very eye opening experience – how much prejudice there is in everyday life that we just accept.

I think the imagery is a brilliant way of getting people to talk about issues surrounding disability.

Ask the Elephant

This article by a deaf doctor encourages students to develop in-depth critical and reflective skills as well as to consider more complex and nuanced issues around disability. In particular the importance of asking disabled people what they require or what they are able to do rather than assuming. Her message that she is no more able to second guess another deaf person's needs or abilities than anyone else, is brought home effectively. The article also addresses the issue of disabled people as healthcare colleagues rather than always patients and how non-disabled colleagues can contribute to an inclusive workplace.

In the absence of a disabled health professional teaching students directly, this article could provide an illuminating and relevant substitute. Students react extremely positively to this article stating that it challenged preconceptions they often did not know they had and shed new light on issues they thought they knew.

Student Feedback

Very interesting to read about how a person with a disability views other people with disabilities, and their admission that they cannot possibly understand another's perspective. It has to a certain extent opened my eyes to how disabled people feel when they are unfairly 'categorised' by society, and the fact that all disabilities AND people are unique, therefore a one rule fits all policy cannot and shouldn't apply.

Points of learning – how can I pick just two? The whole session was filled with new ways to approach disability. It's really valuable to discuss with the other members of the group as our backgrounds and experiences are so varied. Talking with them brought out thoughts and attitudes I didn't know I felt and brought out new ways of thinking and a new understanding of approaching disability.

I'd never read an article like that before and it made me think about the way that I myself think and address patients and how like many people I make many assumptions about people before I have talked to them.

Scenario and Presentation

This session can be run either as an enquiry based learning activity, or independent group work whereby students take the scenario and work out between them how they're going to learn about and present it. The group write up includes an element of reflection on the learning process to encourage students to understand their own knowledge development. This exercise enables students to learn from each other; to learn how to find information, and to understand the dynamics of learning.

Student Feedback

Scenario was interesting and very ethical, engaged all of our interests and we soon got into deep discussion about legal, ethical and clinical factors. Thought this was a really effective method of getting us to work through the problem together, much better than just being lectured. Allowed us to express our opinions and have a debate about different issues.

There are many issues surrounding abortion. I don't want to voice mine as people may disagree.

Some of the sexual content e.g. masturbation etc delivered by carers quite hard to debate ... good to discuss taboo issues and understand the implications of the wider issues.

I really feel motivated to research and find the answers to the questions we asked. I enjoyed the discussion and was pleased to know that I wasn't alone when I found I know little about the issues raised.

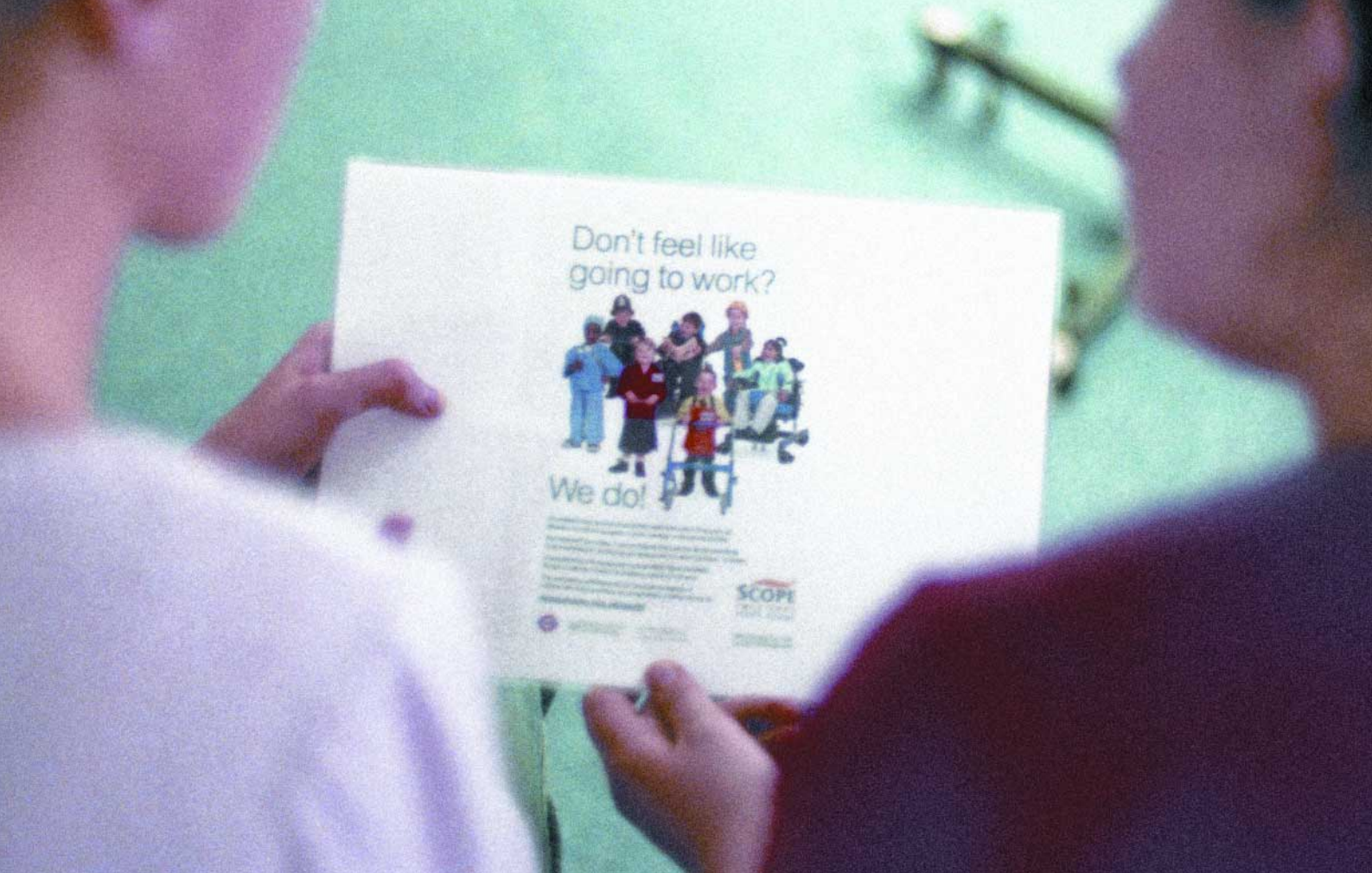
Learned Helplessness

When a patient is disabled or developing an impairment, they often accept unhelpful help because of their vulnerability. This has the negative effect on patient autonomy. Students commented that they had not thought about help being 'unhelpful' before and how, despite the best of intentions, it would be easy for practitioners to contribute to learned helplessness and accidentally abuse their power (see page 64).

Student Feedback

A very relevant session that is of use in most HCPs day to day work, with both the disabled and the 'temporarily ill' etc.

The session made you think about things that I think you would otherwise have taken for granted. It would be so easy to slip into the mistake of 'unhelpful help' and unnecessary paternalism if you hadn't previously thought about it like this.



History of Disability

Students often have a general sense of disabled people's oppression and discrimination, however, it comes as a shock to learn just how extensive and recent much of this history is and how current social practices are still far from inclusive. Students describe this teaching as eye opening and as providing a valuable context to disability equality teaching. Some students felt this session would be suitable at the start of training, however the majority felt that having it at the end gave them an opportunity to draw together different strands of learning.

Student Feedback

It was very insightful and it was the one where I learnt the greatest amount of new information.

Did not know about the history of disability at all. Had no idea of the effect of war on people's attitudes to disability. It had never occurred to me.

I didn't realise just how far back in history discrimination against disabled people began, or quite how long disabled people have been campaigning for their rights.

I think that this session, was very good, as it gave information about disability and also gave a clear cut indication of the way another person can assist another person with a disability to achieve what they want. Very inspired by the interaction between Mark and his PA.

Communicating with Visually Impaired People, D/deaf People and People with Learning Disabilities

These sessions give students practical hands-on experience of communicating with people with a variety of communication needs. Students routinely say that these sessions are amongst the most useful as they can see the immediate, practical relevance to the training. Since both British Sign Language users and adults and children with learning disabilities are amongst the most marginalised people with impairments, it is particularly important that students learn how, as practicing professionals, they can remove the barriers that prevent these groups accessing healthcare.

These sessions work most effectively in small groups as students feel more able to ask questions. Their questions enable them to investigate issues more deeply. The process of questioning involves them using the communication tools and strategies they are learning about, e.g., portable loops and speaking clearly. In addition some adults with learning disabilities may not feel comfortable addressing very large groups.

Student Feedback

Using the microphone ensured everyone listened to each other.

Makes me more confident to approach and deliver a consultation with a patient with a speech impairment.

Really inspiring presentation – brought real issues to light.

It was really good to hear about personal experience from people with learning difficulties.

An eye-opener, extremely informative and enjoyable.

My tutor was completely blind. I thought it was v useful.

The Carer's Perspective

Response to this session has varied enormously over the years, possibly because students might not have seen many carers during their teaching. Also, at times, it has been presented in a very negative and depressing way. The main aim is to question the assumption that family members can automatically take on the carer's role and then to identify alternatives.

Student Feedback

An excellent session, really highlighted many issues I had previously not thought about.

It brought up the issues to think about and remember.

Disability and Ethics

This is a difficult session to facilitate as termination of pregnancy due to impairment is such an emotive topic. What makes this particular topic relevant is the lack of clarity in law as to what 'severely disabled' means when it comes to late termination of a foetus. Despite our aim of focussing on the responsibilities of the health professional when it comes to advising parents of their options, the discussion can become very polarised around the rights and wrongs of termination. Our experience has led us to believe that this element would only work with small groups or possibly when students are directly working in a prenatal setting. It is very important that someone fully conversant with health professionals' duties with regard to the law is involved in the facilitation. Other issues of relevance might include Do Not Attempt to Resuscitate orders or Living Wills, which also involve the four pillars of healthcare ethics (Beauchamp and Childress, 2001). The DRC's website contains resource material on issues of health, medical ethics and disability, including a speech given by Jane Campbell at the Withholding Treatment Conference in 2004 at the Society of Medicine, entitled "Whose 'Best Interests?'" which you may find useful. This can be found at <http://www.drc-gb.org/publicationsandreports/commissionerspeechdetails.asp>

Student Feedback

Ethics was very interesting and important to our future practice – would be better discussed in smaller tutorial groups.

More small group sessions to discuss topics like termination, genetic counseling etc as this is a very relevant part to our futures.

Circular arguments are so frustrating.

Extremely interesting session.

Experiences of Disability

Students generally find this session invaluable. Initially they often express no knowledge of anyone who is disabled but gradually realise they do. Frequently they can recognise the barriers people face and sharing their experiences with those of the tutors broadens their understanding and makes them realise how many misconceptions they have subconsciously held. The students comment that direct contact with a disabled person is what makes these sessions so powerful.

They really enjoy the 'Talk' video as it presents the issues in an imaginative way (for how to obtain copies see page 76).

Student Feedback

It was good to have the experiences of disability explained by disabled individuals.

Excellent presentation. Students were encouraged to relax and ask questions.

Excellent – really learnt and gained a new insight.

Video (Talk) was brilliant – made me realise how cringeworthy I can be without meaning to.



PiP Experiences of Implementation

For institutions like the University of the West of England, Bristol, whose Faculty of Health and Social Care programme is modular, incorporating the PiP learning outcomes could present a challenge as the disability theme is likely to be addressed across a number of modules. The potential exists for the theme to be fragmented or lack coherence. The Faculty has found that using a small group of teachers with experience and expertise in addressing a theme across a programme, allows for greater coherence and consistency in its delivery and these teachers are able to establish clear links with previous learning and future teaching sessions.

Where the module is offered as a 'one off' such as at the University of Bristol, it is important that disability equality education remains an integral theme of the overall medical programme. So strategies need to be put in place that enable the theme to be revisited and re-addressed at pertinent stages of the programme, otherwise it is likely that its importance will diminish.

As a new medical school, the Peninsula Medical School is fortunate to be able to go about planning a course that is not burdened with tradition and past history, but where new ideas and innovations can flourish. The curriculum is organised thematically. Learning activities are varied and include problem based learning, small group work and extensive and early clinical experience. The importance of involving users of health care services is recognized so a User Involvement Group informs, develops and progresses the School's strategy. User involvement has been developing alongside the curriculum and now includes mental health users acting as tutors. There are plans for similar teaching sessions with D/deaf people, visually impaired people and people with learning disabilities, hearing and visual impaired people. These sessions have been designed using the PiP learning outcomes.

Assessment

Research conducted by the DRC, The Leonard Cheshire organisation and our own Delphi consultation has shown that when it comes to ensuring equitable treatment and access to healthcare, disabled people consider a health professional's attitude to be more important than their knowledge or skills.

Students' knowledge and skills are routinely and variously assessed throughout their training however, assessment of students' attitudes and their attitude change is patchy. Even where disability teaching and learning exists in UK undergraduate healthcare courses, it is uncommon for any aspect to be formally assessed. Yet, bearing in mind the repercussions for both patients and practitioners, the need for effective and practical methods of assessing student's skills and attitudes towards disabled people is essential.

The Attitude Towards Disabled People Scale (ATDP)

In the field of disability teaching and learning, the Attitude Towards Disabled People scale (ATDP) dominates attitudinal testing. However, the ATDP scale was first published in 1960 and its language and statements reflect the lack of public awareness about disability that was expected forty years ago. Today, many of the statements strike lay-people as curious, whilst many people working within the field of disability teaching and learning find the scale highly problematic. Although still widely used, its limitations must be acknowledged and its continued use questioned.

At the end of our teaching pilot we asked participating healthcare students to complete the ATDP before asking them to tell us what they thought of the scale. At the same time we asked a control group of healthcare students who had not received training to do the same thing. Both groups objected to the scale. Even though the students who had received training gave more complex explanations for their objection, both groups strongly felt the scale could not reflect their attitudes either because the questions were inherently discriminatory, or because they were unable to give an answer that reflected their views.

Student Feedback

Very generalised questions eg. All disabled people etc.

I found it hard to answer some questions accurately and honestly because the answer scale did not reflect what I wanted to say.

It was very discriminatory it gave the opinion that disabled people are not 'normal' and they are disadvantaged in some way. It addressed disabled people as a collective group and not as an individual, so clear comparisons were hard to make.

I felt the questionnaire treated 'disabled' people as a problem when they are not. It also seems to put disabled people into another group of society.

Observed Scenario – the ‘ROSCE’

In response to perceived problems with the ATDP, the project has designed a formative assessment tool we call a ‘Reversed OSCE’ or ROSCE. Unlike a traditional OSCE which is run separately for each student, in the ROSCE a group of students observe a scenario where a disabled person interacts with various healthcare workers (played by actors) and then individually write down anything that strikes them as noteworthy. The scenario is based on the disabled person’s real life experiences of healthcare provision and involves both good and bad practice in areas that range from body language and vocabulary to clinical and communication skills. The ability to assess a large number of students in a short space of time is becoming more pertinent with the increase in cohort sizes.

The scenario was performed live for our pilot. Students watched it through once and it was then staged again in three sections with time in between each section for students to write their observations. The scenario was subsequently filmed and produced as a DVD which accompanies this document.

Student Feedback

...directly useful to my profession i.e. communication with the patient, direct eye contact, being professional...

Good refresher session after the two days. Made me realise just how different my attitudes are now compared to before.

The (ATDP) questionnaire was really stupid! The acting was good and made me aware of how noticeable poor body language can be.

Final scenario was a good way to end, shows you how you can be discriminatory without meaning to, and highlights the way to and not to behave around a patient.

Is a PA a carer? I don’t know.

Findings

Students felt it was very important to know the scenario was based on real experience, although this was better stated afterwards so that they had no preconceptions of what was expected of them as observers.

Despite being drawn from life, we had been concerned that the scenario might appear extreme. Students acknowledged the likelihood of the scenario happening and in many instances had witnessed similar practice themselves.

Students appreciated the ability to watch good as well as bad practice in action as they felt teaching too often only focused on negative practice.

By not telling students to look for good and bad practice but rather to comment on what they saw, their reactions were more spontaneous and reflexive. Students were aware that they had not picked up on more subtle issues such as eye contact between healthcare workers, the disabled patient and his PA. They therefore felt that the ROSCE would be a valuable tool for cumulative learning if watched at stages in their training, enabling them to see whether their observations developed in comprehensiveness and sophistication.

Students would prefer a live performance, although recorded clips are valuable as an aide memoir for study in their own time. Students also felt they could develop their understanding through active participation, i.e. by directing the action/reaction of performers. From their responses to the ROSCE we could well imagine a group of students telling the disabled character to be more assertive or, if that didn't work, to become aggressive or rude. This, perhaps more than anything would help students understand the frustration and anger some disabled people feel and display.

Potential ways of using this tool might include:

- peer marking - formative assessment and learning from each other.
- anonymous peer marking immediately after the performance/DVD viewing, providing 'real time' assessment and feedback.
- students pick out 5 areas of good practice and 5 of bad practice. Scored against a list with differential marks for nuances. (particularly useful as understanding disability equality and rights is an iterative process and as students progress through a programme they should be able to pick up more subtle issues)
- OSCE stations playing short excerpts of the DVD

Objective Structured Clinical Examination (OSCE)

The University of Bristol has developed an assessment tool for measuring healthcare students' clinical competence and approaches to disability. This is an OSCE on communication with deaf people where both the patient and assessor use hearing aids and lipread. Using the instructions given to the 'patient', the student and the scoring system for the assessor, this OSCE could easily be adapted to apply to visual impairment or learning disability.

Instruction for the deaf 'patient' who uses a hearing aid and lipreads

You are Mrs Smith. You have been in hospital for some investigations. The day before discharge you develop symptoms of a water infection. (These might include burning when passing water and frequently going to the toilet). A doctor on call has been asked to prescribe you a course of antibiotics to take at home. H/She will ask if you are allergic to the antibiotics to which you reply no. He/She has been told you have a hearing impairment but not the degree.

We are examining the students on how they approach you with regard to your hearing, rather than exactly what information they give you. Please wait for them to speak to you before letting them know you can lipread.

Take a look at the marking sheet to see what we expect from the students.

Marking sheet for the deaf examiner who can lipread:

NB: You are awarding marks for what the students do, i.e. their performance, rather than what they know or what they later say they should have done.

Introduces themselves and enquires about the patient's preferred method of communication	0/1/2
Positions themselves facing the patient	0/1
Rhythm of speech slows slightly whilst maintaining clarity	0/1
Use of facial expressions, body language and gestures	0/1/2
Hands chart to patient or writes key words	0/1
Allows time and is patient	0/1
Discretionary point for excellence	0/1
Total	/9

Extra Question:

*In a **real** ward situation what other factors might be important?*

Look for 2 from either: Background noise, finding a quiet place, sufficient lighting, privacy. **0/1**

If student shouts they lose **2** marks.

Final mark out of 10 =

Information for examination candidate:

You are covering a colleague for the afternoon and have been asked to see Mrs Smith who is about to go home. An MSSU has come back showing a urinary tract infection with E.Coli sensitive to trimethoprim. You have written out the chart (provided) and have to explain to Mrs Smith the reason for the drug and ask if she is allergic to it. You then have to tell her the dose and how many days to take the medication. She has a hearing impairment.

The candidate should have access to a drug chart written up for trimethoprim 200mg twice daily for five days.

This station ran for 5 minutes. The marking sheet and information for the patient and examiner were taken directly from handouts the students receive on the course. The people who ran the OSCE gave us invaluable feedback, including the temptation of the examiner to award marks if students suddenly realise what they were supposed to do as they were leaving the room. We had to adapt the form to make it clear that the marks were given for actual performance, as this is a test of skills rather than knowledge. Also examiners noted that some students were excellent and conveyed all that was needed in a few sentences. Thus a discretionary point for excellence was included and the examiner was allowed to say to the candidate that they had completed the task even if they had a few minutes left.

The marking profile using this OSCE was not significantly different from other stations successfully differentiating those students with very poor communication skills around hearing impairment. This offers the potential for formative as well as summative assessment and revision of the skills required.

Resource Pack and Toolkit

Glossary of abbreviations

ATDP	Attitude Towards Disabled People Scale
BCODP	British Council of Disabled People
BSL	British Sign Language
PiP	Partners in Practice
DDA	Disability Discrimination Act
DET	Disability Equality Teaching/Training
DRC	Disability Rights Commission
E/PBL	Enquiry/Problem Based Learning
HCP	Healthcare Professional
OSCE	Objective Structured Clinical Examination
PA	Personal Assistant
ROSCE	Reversed OSCE
SENDA	Special Educational Needs and Disability Act

What is Disability Equality Training?

Disability Equality Training (DET) promotes equal opportunities for disabled people by enabling participants to identify and address discriminatory forms of practice towards disabled people. DET aims to initiate action towards creating a society in which disabled people have the right, opportunity and choice of realising their potential as fully functioning citizens. DET is about:

- the social model of disability
- examining the barriers faced by disabled people in society
- questioning stereotypes, myths and misconceptions about disabled people
- a commitment to change

The Delphi Process

The Delphi Process is a means of reaching consensus through structured consultation between a group of people who may have very different perspectives and fields of expertise. The process is questionnaire based, anonymous and as participants do not meet, any number can be involved (in this project people with learning disabilities and Deaf people did meet to ensure their inclusion on an equal basis). Participants respond to a number of statements using a ranking system. Responses are analysed centrally and then fed back to all participants, enabling them to change their minds and re-rank their answers if they wish in light of opinions expressed by the group. This process is repeated until consensus is reached. At the end, a statistical response is arrived at for each statement that equates to the strength of opinion felt by the group.

The Delphi consultation process is explained in 'Qualitative Research in Healthcare' Eds Nicholas Mays and Catherine Pope BMJ Publishing Group 1996.

The original PiP Delphi consultation document can be viewed at <http://www.bris.ac.uk/pip/form.htm>.

The consultation document was divided into twelve overarching themes which were each in turn subdivided into descriptors. After ranking, the top 9 themes were:

- 1** Enable the disabled individual to contribute to decision making around their care as part of the care team/management/treatment
- 2** Demonstrate an understanding of the barriers that prevent equality of access to healthcare and their impact on disabled people
- 3** Demonstrate effective two way communication and use of appropriate communication formats and skills
- 4** Demonstrate an awareness of their own, societal and institutional assumptions about the abilities, identity and behaviour of disabled people
- 5** Reflect critically upon their interactions with disabled people as a guide to their own future development and learning
- 6** Demonstrate the ability to critically reflect on their practice and the practice of others
- 7** Demonstrate the ability to actively and appropriately involve carers, personal assistants and/ or advocates
- 8** Demonstrate an understanding of the power of language
- 9** Demonstrate an understanding of the social model of disability

Ask the Elephant

Reprinted from The Lancet.

Kvalsvig, A. 2003: 362(9401): 2079-2080. Reprinted with permission from Elsevier

Friends, readers, colleagues: lend me your ears... I would use mine, but they don't work so well these days.

Yes, in the last 15 years or so I've heard all the deafness jokes, and made a few too. I also know off by heart those reassuring little phrases:

"It doesn't seem to bother you." (Oh yes it does.)

"You'll be fine." (How can you know that?)

"You don't look deaf." (Ummm, thanks.)

And my personal favourite:

"Well, at least you're not blind." (There may well be a sensible response to this, but so far it has eluded me.)

I do understand that urge to reassure. And I understand all too well how easy it is to blurt out something silly when you've no idea what to say. But I resent these empty reassurances – just as much as I resent it when hearing people earnestly explain to me what a deaf person cannot do.

Explaining your own disability can be difficult, however. I've always felt a bit hopeless about those precious 15 minutes once a year with the specialist.

"So, how are you getting on?" they ask. Oh dear. It's like that old exam joke:

"Summarise the universe. Give three examples." In the face of such impossibility my brain always turns to fluff and I end up replying feebly, "Oh... fine, really". Zero points for eloquence.

It often used to happen that soon after my appointment I'd be back in outpatients – this time on the other side of the desk. "So, how are you getting on?" I would ask. "Oh... fine, really" the patient would reply, and we'd shrug our

shoulders and sigh. The single most important insight I have gained from being a disabled doctor is that I really have no idea what life is like for my patients.

When I meet a disabled person I have to keep reminding myself that I must not try to guess what their difficulties and concerns will be. To someone with medical training, this goes very much against the grain. Doctors are supposed either to know these things, or to be able to make an educated guess. We are trained to use information about probability ("82.3% of elephants dislike Brussels sprouts") in order to make decisions about individuals ("OK, better give Nellie some carrots"). Another crucial technique is to deal with an unfamiliar situation by extrapolating from what you already know ("Big animals eat more than small animals, so... LOTS of carrots then").

This is a very effective way to make decisions and you can't practise medicine without it, but it does raise a rather obvious question: why don't you just ask the elephant? Put some food out and see what she nibbles. Why all the fancy guesswork when you can find out the simple way?

Unfortunately, in medicine, asking the elephant is not always possible. The "elephant" may be a disease process or organ system that simply isn't amenable to direct interrogation. That's why managing uncertainty is a central skill in the art (or science) of being a doctor. The problem is that some of us don't know when to stop speculating and just ask.

I wish I could have a pound for every time a colleague has said to me, "Of course, haha, you can't do cardiology". This is the number one favourite in the Amateur Career Advice for Deaf Doctors stakes. I used to go along with it,

but now I'm a bit sceptical. Why shouldn't I do cardiology? Well, obviously, because cardiologists listen to people's hearts all day long and I couldn't do that.

But do they? And couldn't I? All the cardiologists I know are wizards with the echoprobe. Time and time again I've stood gaping at the image on the screen – apparently a snowstorm broadcast on a badly tuned black and white television – while the cardiologist explains confidently. “Yes, now you can see the left ventricle just here, and over here you can see that rather abnormal looking valve, and now...” – more blizzard – “now in this view you can see the ventricular septal defect very clearly...”. I nod wisely and feel totally inadequate.

Paradoxically, it may well turn out that cardiology is an excellent career for a deaf person (but not me, as I've obviously no talent whatsoever). Cardiologists have at their disposal all sorts of ways of gaining information about the heart, and many of them are far more informative than the stethoscope.

In any case, you don't need good hearing to use an electronic stethoscope. These used to be horribly crude but they are becoming cleverer every year. Current models can produce a visual waveform and even make a basic analysis of the heart or lung sounds. I'm still waiting for the model that can undo all the 24 million poppers on an average baby vest, but no doubt this is already in development.

It doesn't take any leap of imagination to predict that the stethoscope as we know it could soon go the way of the dinosaurs. But you can bank on it, there'll still be doctors saying, “Of course, you can't do cardiology”. More worryingly, I do fret that perhaps right now, somewhere in the world, a medical student with impaired hearing is being fed this plausible little

piece of advice. And maybe this medical student has the potential to be an enormously talented cardiologist who could save thousands of lives and revolutionise the field. Only they won't, because it didn't occur to their advisor to stop and think... or to ask the elephant.

Now, I'm not suggesting that all deaf doctors should rush off and train as cardiologists, or that auscultation is always easy when you're deaf. The important point, to me, is that a seemingly very sensible piece of advice is actually quite wobbly when you take a closer look.

Assuming that someone cannot do something is destructive; but so is assuming that they can. I mentioned earlier the things people say in a desperate attempt to reassure me that deafness isn't so awful. But it is awful and the problems can be difficult to solve. For example, a common myth about deafness is that if you lipread or wear a hearing aid, or both, your hearing will be miraculously restored. If only. Hearing aids are very useful for some kinds of deafness, but not mine. The best I can expect from a hearing aid these days is a huge amount of non-specific noise. It's very tiring, but not half as tiring as lipreading. You can only see a small fraction of the vowels and consonants by watching someone's mouth. The rest is done by following the cadence of speech, watching facial expression, matching possible words to the context – it's like solving crossword puzzles at breakneck speed, and it is exhausting.

My biggest challenge in clinical work was not to follow what people were saying – you can always get there eventually – but fatigue. The effort required to understand every single word on a ward round was enormous, especially in a noisy ward (and paediatric wards are in a class of their own here). My level of tiredness at the end of the day was very strongly related to the type of work I'd been doing that day. Conversely, my ability to “hear” fluctuated with my level of tiredness.

This variability can be confusing. I often get the feeling that people I meet are trying to get to

grips with my deafness by creating a sort of mental accounts sheet. In the left hand column, “things she can do”; in the right hand column, “things she can’t do”. I wish it were that simple. It’s taken me a good few years to realise that there’s almost nothing that I absolutely 100% can’t do. I no longer ask myself, “Can I do this?”. The real question is, “Am I prepared to pay the price?”. The cost may be very high in the currency of disability: effort and frustration.

I always knew that my days as a clinician were numbered; that sooner or later, deafness would end it all. For years, I assumed along with everyone else that there would be a well-defined moment when I could no longer deliver a good standard of care to my patients. My plan was to anticipate this moment and stop working before it occurred.

The reality was quite different. I just became more and more exhausted by the combined demands of deafness and a busy job. Eventually, I decided that it wasn’t worth going on and that was that. There was no moment where “can do” mutated into “can’t do”.

In the same way, I struggle to answer questions about how deaf I am. When I’m curled up on the sofa reading a book, I’m not deaf at all. When I blow the dust off my violin and wonder at the way it still sits so lightly in my hands... well, I feel pretty deaf, then.

My hearing level as measured by an audiogram has limited value. I cope much better now than I did 15 years ago, despite the fact that my audiograms have deteriorated from “could do better” to “abysmal, see me after class”. Humans are adaptable creatures and I have learned an awful lot of useful tricks over the years. For this reason, I’d never assume that a slightly deaf doctor will automatically cope better than a very deaf one.

I am terribly suspicious of abstract discussions about the clinical abilities of disabled doctors. “Disabled” seems to be synonymous with “in a wheelchair” to some people. They worry about how this hypothetical disabled doctor will cope

with stairs. Personally, I’m happy to say that I’ve never been troubled by stairs at work.

There are so many different types and levels of disability, so many different specialties, so many different tasks within each specialty. I’ve discovered from my own experience that it’s very hard to predict what an individual doctor will find easy or difficult. Add to that the fact that everyone has good days and bad days; that colleagues vary in helpfulness; and that technology is evolving almost at the speed of thought. How can vague generalisations be meaningful here?

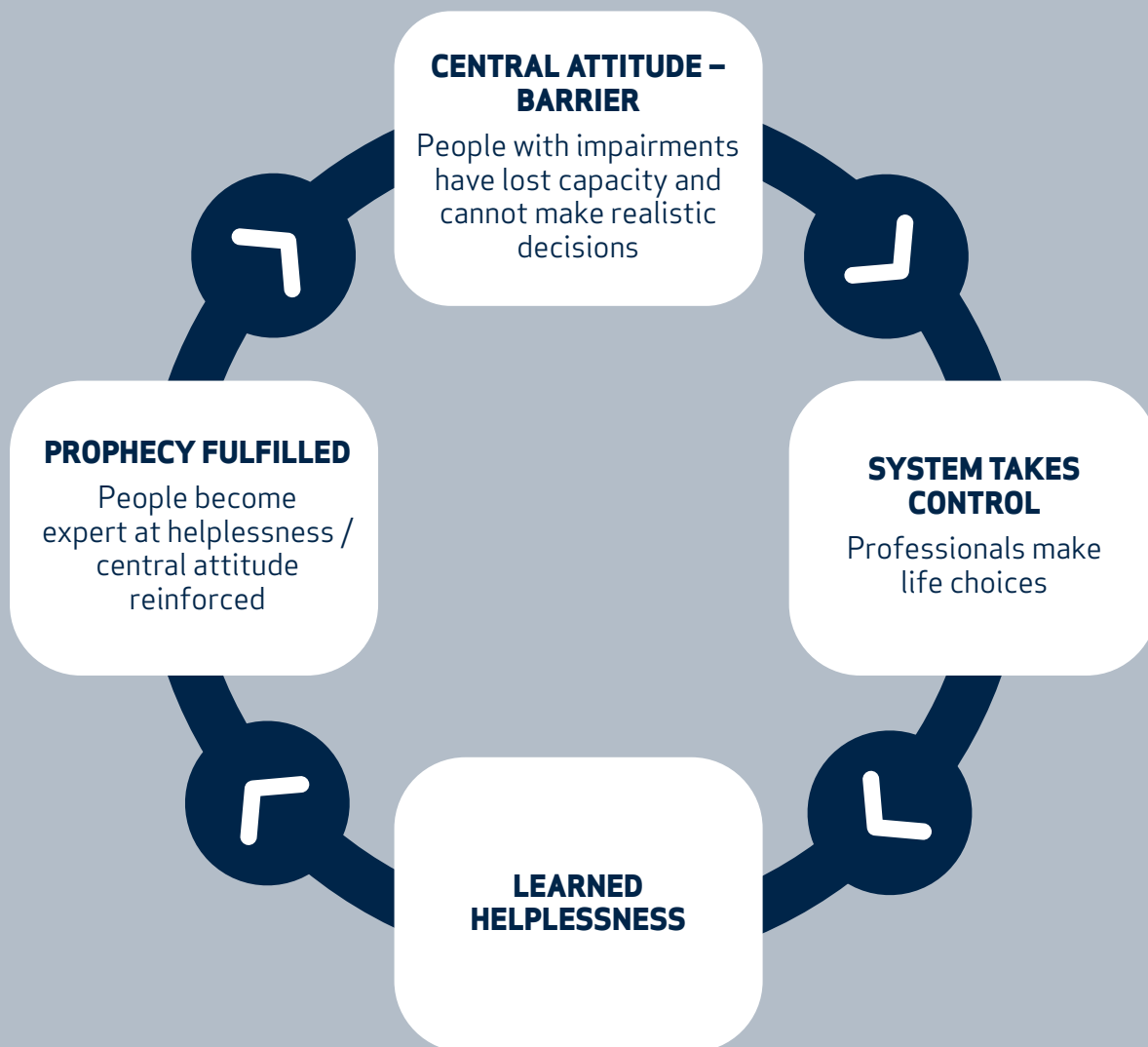
To me, there doesn’t seem much point in standing around eyeing the elephant and theorising about its dietary needs. What’s more, I think disabled doctors are a far more heterogeneous group even than elephants. I doubt if any summary statistics can predict the wishes (“78.6% of disabled doctors enjoy minty peas”) or abilities (“26.4% of disabled doctors can’t tell a parsnip from a potato”) of a particular individual. I’m not too worried about this. As in so many areas of life, knowing how little you know is the important thing.

The disability I know best is deafness. The profession I know best is medicine. So I accept that I’ve no idea how life is for, say, an accountant with cerebral palsy. But I do at least know what not to do if I should meet such a person. I won’t automatically assume that they can’t do certain things – nor will I blithely reassure them that they can. I’ll steer away from the all-or-nothing questions (“Can you do X? Can you do Y? Can you do Z?”) and try to build up a picture of a more complex reality. Above all, I will let them tell me how it is. It’s amazing what you can learn when you just ask the elephant.

Learned Helplessness

The Disabling System

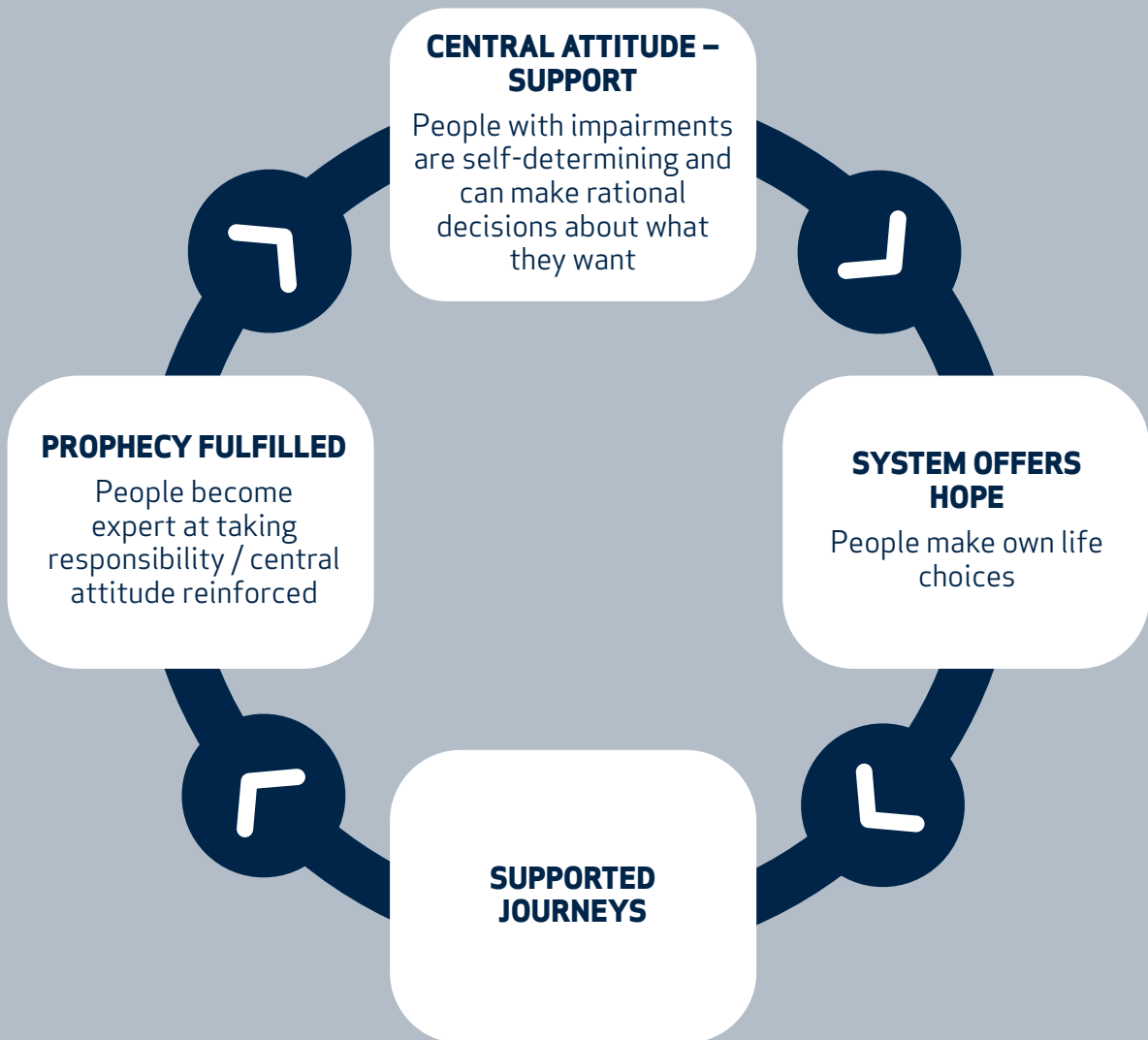
Learned Helplessness



From Deegan, 1992, *Psychological Rehabilitation Journal* 15, 3-19
Thomas, 1997, *Sociology of Health and Illness* 19, 622-643

The Enabling System

Supporting Autonomy



Languages and Images Reference Material

The British Film Institute has a great deal of information available online that explores the representation of disability and disabled people in moving images. They have also produced a resource pack for teachers. Visit:
<http://www.bfi.org.uk/education/resources/teaching/disability/guide.html>

For an introduction to the way art and visual images are constructed and the gendered gaze, the classic text is John Berger's *Ways of Seeing*, London, 1990.

The Disability Discrimination Act (DDA) – its relevance to healthcare

Detailed information on the DDA can be found at:

www.direct.gov.uk/DisabledPeople/RightsAndObligations/

www.disability.gov.uk/dda/

www.drc.org.uk

The DDA defines disability as a substantial, long term physical, sensory or mental impairment that has an effect on a person's ability to carry out normal day-to-day activities.

The original Act of 1995 made it unlawful for a service provider to refuse to serve a disabled person, to offer a substandard service, or to provide a service on different terms, purely on the grounds of disability. The term 'service' explicitly covered health services.

The 2005 Act is more human rights orientated. It has introduced a new duty on public authorities to:

- eliminate harassment of disabled people
- eliminate discrimination against disabled people
- promote equality of opportunity between disabled people and other people
- promote positive attitudes towards disabled people
- encourage participation by disabled people in public life

Models of Disability

Individual or Medical Model

This model sees each disabled person as an individual bound up with their impairment(s) – their medical condition or malfunction. They ‘suffer’ from and are defined by their impairments. The impairment(s) is/are seen as a ‘problem’. The individual person must strive to ‘overcome’ their impairment(s). The aim should be to behave/act as ‘normally’ as possible, fitting in with the rest of society as far as practicable.

It is assumed that every disabled person wants to be ‘cured’, or to be ‘normal’. Cures are seen as lying with medicine and the doctors and therapists who work to make people better, while the main responsibility to strive to fit in lies with the disabled person. Society and its members are often uncomfortable with disabled people who cannot be ‘cured’, or who do not behave/act as normal.

Social Model

This model sees people as having impairment(s) – a medical condition or malfunction. Disabled people are disabled by physical, organisational, and/or attitudinal/behavioural barriers in society. For example: It is not an inability to climb steps that excludes disabled people from many public buildings, but the fact that they were built with steps in the first place. Deaf people are prevented from taking a full part in meetings not by their hearing loss, but because the meetings’ facilities do not include sign language interpreters and/or induction loops etc.

‘Disability’ refers to the restrictions society causes through discrimination/ignorance/prejudice, not the impairment(s).

The aim of the social model is a world fully accessible to all. In such a world discrimination against disabled people does not exist and everyone can participate fully. This analysis says that if such a society could be created, there would be no disabled people, as everyone would have the same opportunities.

General Advice for Ensuring Inclusive Practice

It is perfectly acceptable to offer assistance to a disabled person but give them time to accept your offer before taking any action.

Always talk to the disabled person, not their friend/carer/assistant.

A wheelchair is part of a person's individual space, so leaning on it is invasion of this space.

When offering assistance to a visually impaired person, allow them to take your arm. Never grab them without warning. Warn them of steps and other obstacles before they occur.

Never stroke a guide/hearing dog without asking the owner's permission. The dog is working and you will distract them.

Conversation

If in doubt, ask.

Never pretend you have understood a disabled person if you haven't. Ask them to repeat themselves.

Use your natural language. Phrases such as "Would you like to look at" and "Let's step over here" will not cause offence.

If you meet a visually impaired person, introduce yourself and others by name. Always say when you are leaving. It is very embarrassing to be left talking to an empty space.

How to improve your communication with someone who has a speech impairment

Give your whole attention to them and be patient.

Do not finish sentences, correct or speak for them.

When possible, ask questions that require short answers, a nod or shake of the head.

How to improve your communication with someone who has a hearing impairment

Ask rather than assume about the best way to communicate.

Make sure you have their attention.

Ensure that background noise is minimised.

Keep eye contact and your head fairly still.

Ensure there is sufficient lighting.

Ensure your mouth and face are not hidden.

Maintain a normal speech rhythm perhaps slowing down slightly if you talk quickly.

Shouting is not acceptable.

Facial expressions, body language and gestures improve communication.

Write down key words and/or rephrase a sentence.

Give the subject of the conversation first.

How to improve your communication with someone who is learning disabled

Do not give too much information at one time.

Check that they have understood you - ask them to repeat information back to you if necessary.

Do not let supporters/carers take over and answer questions unless the learning disabled person has asked for their help.

Explain clearly and simply any procedure before you undertake it.

If they are unable to communicate, ask their support person if they have any special ways in which they communicate and use these if you can.

Fuller versions and other materials are available on the website:

<http://www.bris.ac.uk/pip.htm>

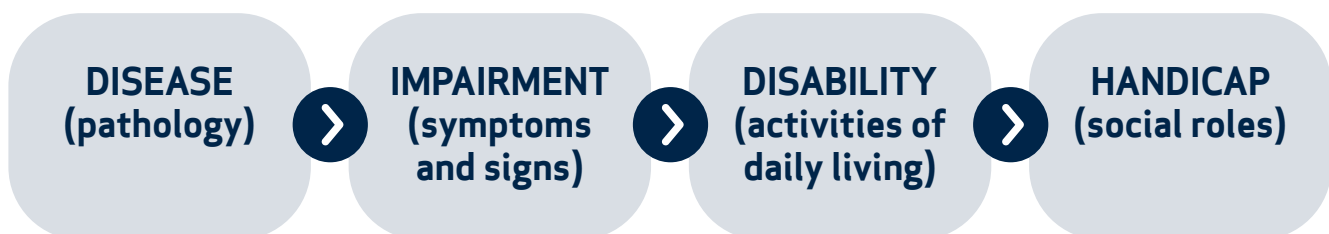
World Health Organisation (WHO) classifications

Developments and usefulness

The full version of the latest International Classification of Functioning, Disability and Health (WHO-ICF) can be found at <http://www.who.int/icf>

Background

The 1980 version of the WHO Classification of Impairment, Disability and Handicap (WHO-ICIDH) was based on “consequences of disease”. Simplifying it, the following relationships were used:



An example might be a woman with rheumatoid arthritis. The pathology would include inflammation of the synovial lining of her joints. The impairment might include pain, swelling and stiffness of her joints and the disability would relate to such activities as dressing, walking and/or housework. The handicap might be seen as her inability to work or to care for her children in the way that she wants. The framework allowed individuals to be seen as having their own specific issues, even within a particular disease process.

Clinically it seemed useful in targeting different consequences of the disease. In the above example, the woman could be treated with biological agents to target the pathology or anti-inflammatory drugs to reduce pain and swelling. Symptoms could also be helped by application of cold compresses or the use of splinting e.g. of the wrists. These would all help daily activities but aids and equipment might also be useful. At the handicap level arranging transport might be sufficient to keep her at work; possibly extremely important to her in terms of social contact, self-esteem and finances. Keeping all four levels of disease consequence in mind meant that the focus did not just stay with the pathology and impairment.

Although useful, the classification had some major flaws:

- The sequence appeared linear and directional: However someone who is HIV positive or recovering from a mental health illness might have no impairment or disability and yet face discrimination and stigmatisation in terms of work, travel, insurance etc. Facial or other disfigurement could have similar consequences. Equally the inability to carry out daily activities can create new pathologies and impairments, such as muscle wasting or pressure sores.
- The focus was always on the negative aspects of disease: The concentration on what people could not do meant that abilities were easily overlooked, fostering a feeling of helplessness and dependence on professional experts.
- The term 'handicap' is no longer acceptable: As language evolves words fall out of usage or take on particular significance and handicap is seen as pejorative.

After extensive consultation the WHO International Classification of Functioning, Disability and Health (WHO-ICF) was finalised in 2001. It has become a "components of health" classification.

A major aim of the ICF classification is to establish a common language for describing health and health-related states in order to improve communication between different users, such as healthcare workers, researchers, policy-makers and the public, including people with disabilities.

It is often thought that the ICF is only about people with disabilities when in fact it is about *all people*. The health and health-related states associated with all health conditions can be described using ICF i.e. it has universal application.

Functioning is an umbrella term encompassing all body functions, activities and participation; similarly, *disability* serves as an umbrella term for impairments, activity limitations or participation restrictions. The ICF also lists environmental factors that interact with all these constructs.

Scope of ICF

The ICF organizes information in two parts. Part 1 deals with Functioning and Disability, while Part 2 covers Contextual Factors. Each part has two components:

1 Functioning and Disability

The Body component comprises two classifications, one for functions of body systems, and one for body structures.

The Activities and Participation component covers the complete range of functioning from both an individual and a societal perspective.

2 Contextual Factors

Environmental Factors is the first component of Contextual Factors. They have an impact on all components of functioning and disability; from the individual's most immediate environment to the general environment. Environmental Factors are extrinsic to the individual (e.g. the attitudes of the society, architectural characteristics, the legal system) and can either facilitate or hinder the individual.

Personal Factors is also a component of Contextual Factors but they are not classified in ICF because of the large social and cultural variability associated with them. They include gender, race, age, fitness, lifestyle, habits, coping styles and other such factors. Their assessment is left to the user, if needed.

Overview of ICF components

DEFINITIONS

In the context of health:

Body functions are the physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

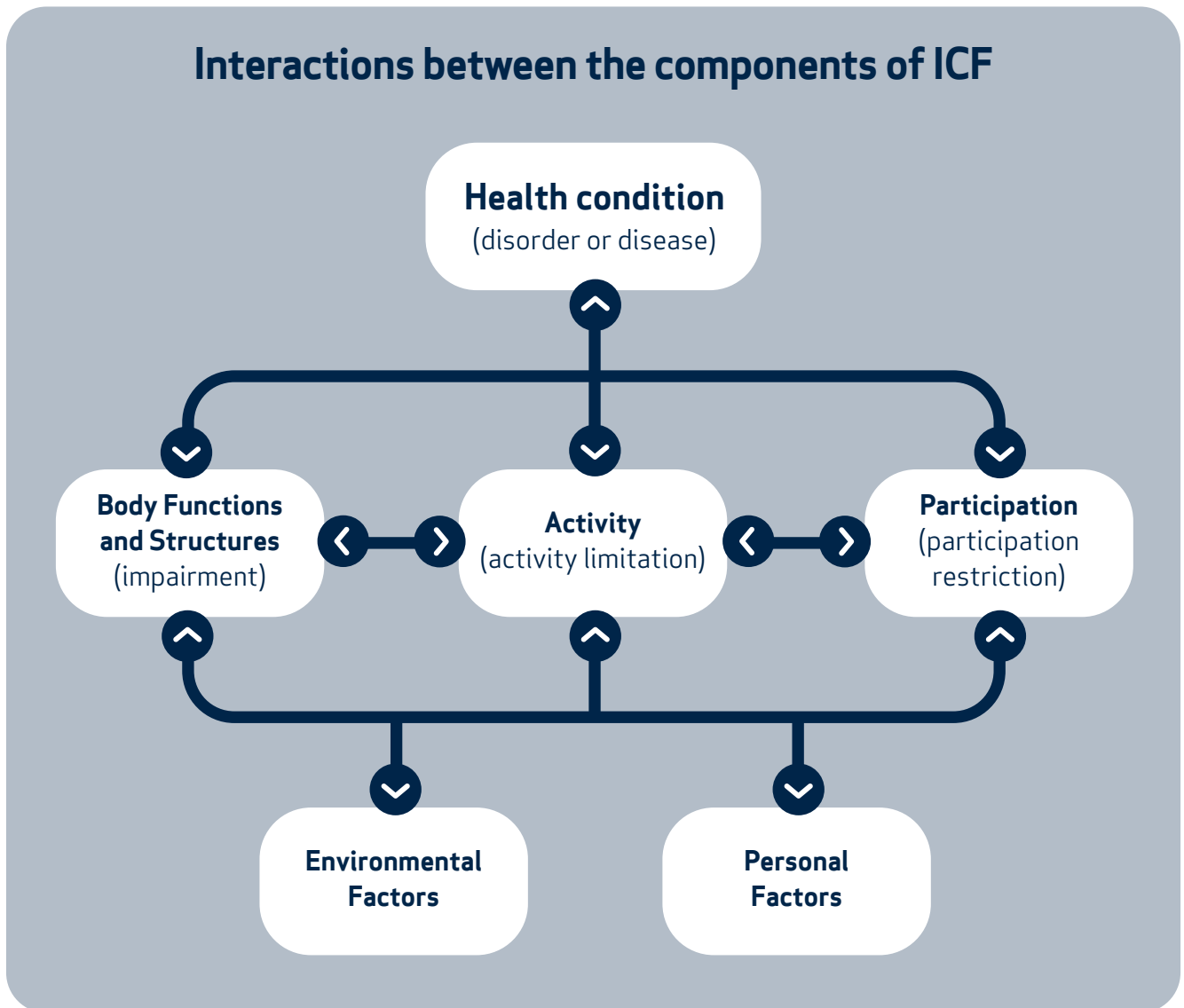
Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

In order to visualize the current understanding of interaction of various components, the diagram presented may be helpful:

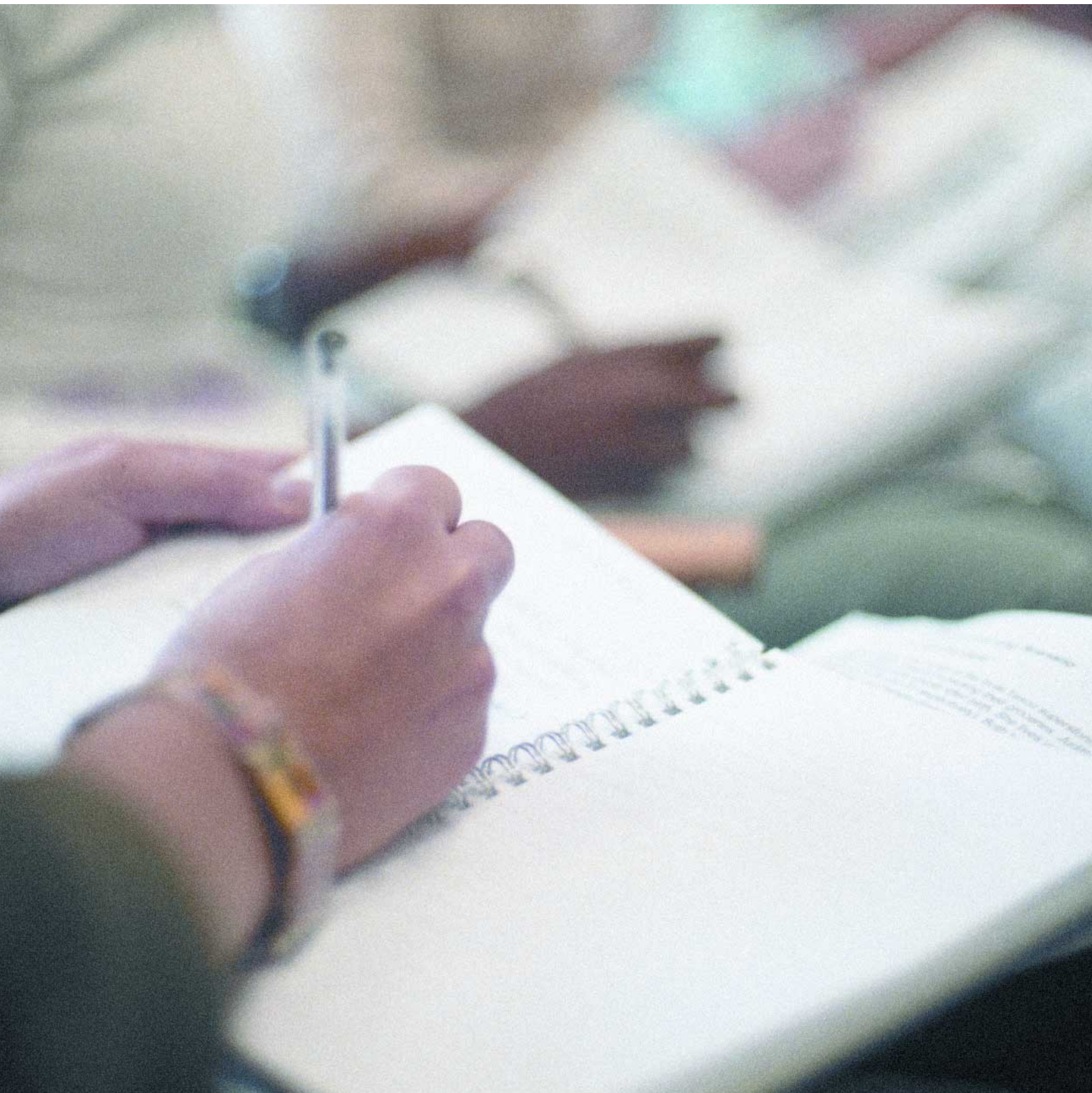


In this new diagram, an individual's functioning is a much more complex interaction between the health condition and contextual factors (i.e. environmental and personal factors). There is a dynamic interaction among these entities. Interventions in one entity have the potential to modify one or more of the other entities.

Returning to the original example of the woman with rheumatoid arthritis, the healthcare team now have a much more realistic model of the complexities of the interaction between a health condition and contextual factors. This will help them not only look at an intervention such as splints but be able to understand when personal factors could lead to the woman deciding not to use splinting because of particular lifestyle issues, such as working in a place where her hands and wrists are always on show. The inclusion of environmental factors means that health professionals are more likely to use their expertise as a

resource for the patient to use to manipulate their environment, such as this patient's home or workplace. But there is also an obligation for health professionals to consider their own attitudes and assumptions around issues of functioning, for instance, this patient's rejection of the use of splinting at work, or turning down a particular drug that has been advised.

As with any model there are criticisms, not least because definitions are often based on population norms. These can be useful for diagnosis or the monitoring of therapy. For the person with the impairment it is her or his own functioning to meet personal goals and aspirations that are important.



Key Contacts

Disability Rights Commission

The DRC is an independent body established in April 2000 by Act of Parliament to stop discrimination and promote equality of opportunity for disabled people.

The DRC website has an extensive list of up to date, useful contacts, including links to disability, advisory, governmental and research organisations.

www.drc-gb.org

The Centre for Disability Studies

The CDS is an interdisciplinary centre for teaching and research at the University of Leeds. It aims to promote international excellence in the field of disability studies and it hosts the Disability Archive UK.

<http://www.leeds.ac.uk/disability-studies/index.htm>

Disability Reading List

The Disability Archive at the University of Leeds has many relevant disability texts available online. <http://www.leeds.ac.uk/disability-studies/archiveuk/>

Essential Texts

Disabled People Using Hospitals, A Charter and Guidelines.

Royal College of Physicians, 1998

Doubly Disabled - Equality for Disabled People in the New N.H.S. Access to Services

NHS Executive, 1999

One in Four of Us: the Experience of Disability

The Disability Partnership, *London Disability Partnership, 2005*

Special or Different

The Disability Partnership, *London Disability Partnership, 2003*

Disability and the Life Course

Priestly, M., *Cambridge University Press, 2001*

Disabling Barriers – Enabling Environments

Swain, J., French, S., Barnes. C., Thomas, C. (eds), *London, Sage Publications Ltd 1998*

Disability Theory: Key Ideas, Issues and Thinkers, in Barnes et al. (eds.)

Thomas, C., *Disability Studies Today. Cambridge: Polity Press 2002*

Accessible Health Information

Clarke, L., *Central Liverpool NHS Primary Care Trust 2002*

Disabled Students Disabled Doctors – Time For a Change?

Roberts, T.E., Butler, A., Boursicot, K.A.M., *Higher Education Academy LTSN-01 Special Report 2005*

The Social Model of Disability: An Outdated Ideology?

Shakespeare, T., Watson, N., *Research in Social Science & Disability, Volume 2, pp 9-28, 2002*

Disability – definitions, value and identity

Steven D. Edwards, *Oxford, Radcliffe Publishing Ltd 2005*

Other Useful Teaching Resources

The Disability Rights Commission has launched an accessible DVD version of its award-winning short film 'Talk!'. The film, directed by Matthew Parkhill, portrays a society in which non-disabled people are a pitied minority and disabled people lead full and active lives. You can order a free copy via their website.

The Disability Rights Commission's policy statement on health can also be found on their website.

Links can be made between your disability equality teaching and the Department of Health's Long-term Conditions National Service Framework (NSF) which was launched in March 2005. Information on the NSF can be found at:

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/fs/en

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- Wells, T. et al. (2002) Disability teaching for medical students: disabled people contribute to key teaching elements. *Medical Education*, 36, 788-792.

Self-Assessment Tool for the Teaching and Learning of Disability to Undergraduate Healthcare Professionals

General Information

This assessment should be completed by the person or persons who have responsibility for disability teaching and learning across the curriculum within your institution.

As a first step, it may be helpful to construct a list of people to whom this tool should be passed. They in turn could contribute names of others who also have a significant function. This centrally held list will enable monitoring of the progress of the assessment.

Circulation list for comment and completion of disability teaching and learning assessment tool

Use this form to monitor and review progress of the assessment process.
 Rows and columns may be added as required.

Course component	Name	Dept	Contacted/ circulated	Completed/ returned
Curriculum (design, review, content and implementation)				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Teaching and learning (teaching methods, ITC, ethics, clinical skills, communication skills, professionalism, clinical sciences, basic sciences, etc)				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Assessment (MCQ lead, written papers lead, OSCE lead, portfolio lead, etc)				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Quality assurance and curriculum governance				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>

Course component	Name	Dept	Contacted/ circulated	Completed/ returned
Staff development				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Evaluation				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Modules (identify by name)				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Courses (identify by name)				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>
Themes (identify by name)				
1	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/>	<input type="checkbox"/>
4	<input type="checkbox"/>	<input type="checkbox"/>

Please tick below to indicate your area(s) of responsibility

- | | |
|---|---|
| <input type="checkbox"/> Curriculum | <input type="checkbox"/> Quality assurance and governance |
| <input type="checkbox"/> Teaching and learning | <input type="checkbox"/> Staff development |
| <input type="checkbox"/> Assessment | <input type="checkbox"/> Evaluation |
| <input type="checkbox"/> Modules (identify by name) | |
| <input type="checkbox"/> Courses (identify by name) | |
| <input type="checkbox"/> Themes (identify by name) | |

Do you carry any responsibility for some aspect of disability teaching and learning? Yes No

1 Within your institution are you aware of any documented aims, objectives or outcomes covering the teaching and learning of disability issues? Yes No (Go to Q3)

2 If you answered Yes to 1 – Do you have a copy of this/these documents? Yes No
 or **Do you know where to obtain them?** Yes No

3 Are you aware if disability teaching and learning takes place as part of:
 Please tick one or more as appropriate

- a** A stand alone course or module?
- b** As part of a larger course or module?
- c** As part of an integrated theme(s) within the curriculum?

4 Are you aware if disabled people are involved in the curriculum?	In the curriculum overall	In your area of responsibility	Do not know
a As curriculum designers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b As teachers or tutors in small groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c As lecturers/co-lecturers in large groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d As patients (e.g. as cases for bedside, outpatient or other teaching where the involvement is largely passive)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e In other roles (please specify below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f			
g			
h			
i			

- 5 **Do you know how many staff involved in disability teaching and learning have had specific disability equality training?** *Approximate percentage ranges*
- | | | |
|----------|---------------------------------------|-----------|
| a | <input type="checkbox"/> All | 100% |
| b | <input type="checkbox"/> Most | 75% - 99% |
| c | <input type="checkbox"/> The majority | 50% - 74% |
| d | <input type="checkbox"/> Some | 25% - 49% |
| e | <input type="checkbox"/> Few | <25% |
| f | <input type="checkbox"/> None | 0% |
| g | <input type="checkbox"/> Do not know | |

- 6 **Do you know how many staff involved in disability teaching and learning within your area of responsibility have had specific disability equality training?**
- | | | |
|----------|---------------------------------------|-----------|
| a | <input type="checkbox"/> All | 100% |
| b | <input type="checkbox"/> Most | 75% - 99% |
| c | <input type="checkbox"/> The majority | 50% - 74% |
| d | <input type="checkbox"/> Some | 25% - 49% |
| e | <input type="checkbox"/> Few | <25% |
| f | <input type="checkbox"/> None | 0% |
| g | <input type="checkbox"/> Do not know | |

7 **Are you aware if the teaching and learning within the curriculum is based on a specific model of disability?** Yes No

8 **If you answered Yes to Q7 - Which model of disability is utilised?**

a Social model

b Medical (individual) model

c Other (please specify)

9 **Are you aware if the teaching and learning within the area of your responsibility is based on a specific model of disability?** Yes No

10 **If you answered Yes to Q7 - Which model of disability is utilised?**

a Social model

b Medical model

c Other (please specify)

11 **Is the student learning around disability issues assessed?** Yes No

12 **If the answer to Q11 was yes –**

- a Is/are the assessment(s) formative* only? Yes No Do not know
- b Is/are the assessment(s) summative** only? Yes No Do not know
- c Is/are the assessment(s) mixed formative and summative? Yes No Do not know

13 **In what form do the assessments take place?**

Please tick box(es) below

	Formative*	Summative**
Multiple choice questions	<input type="checkbox"/>	<input type="checkbox"/>
Extended matching items	<input type="checkbox"/>	<input type="checkbox"/>
Patient management problems	<input type="checkbox"/>	<input type="checkbox"/>
Short answer questions	<input type="checkbox"/>	<input type="checkbox"/>
Essay questions	<input type="checkbox"/>	<input type="checkbox"/>
Objective structured clinical examinations	<input type="checkbox"/>	<input type="checkbox"/>
Reflective writing	<input type="checkbox"/>	<input type="checkbox"/>
Project report	<input type="checkbox"/>	<input type="checkbox"/>
Portfolio analysis	<input type="checkbox"/>	<input type="checkbox"/>
Presentation	<input type="checkbox"/>	<input type="checkbox"/>
Supervisor report	<input type="checkbox"/>	<input type="checkbox"/>
Peer assessment	<input type="checkbox"/>	<input type="checkbox"/>
Group assessment	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>

* **Formative** assessments are for student feedback and do not impact on progression

** **Summative** assessments are “must pass to progress” high stakes assessments

Top 9 Themes (Delphi)	Teaching and Learning*	Assessment**
1 Enable the disabled individual to contribute to decision making around their care as part of the care team/ management/ treatment	<input type="checkbox"/>	<input type="checkbox"/>
2 Demonstrate an understanding of the barriers that prevent equality of access to healthcare and their impact on disabled people	<input type="checkbox"/>	<input type="checkbox"/>
3 Demonstrate effective two way communication with disabled people and a use of appropriate communication formats and skills	<input type="checkbox"/>	<input type="checkbox"/>
4 Demonstrate an awareness of their own, societal and Institutional assumptions about the abilities, identity and behaviour of disabled people	<input type="checkbox"/>	<input type="checkbox"/>
5 Reflect critically upon their interactions with disabled people as a guide to their own future development and learning	<input type="checkbox"/>	<input type="checkbox"/>
6 Demonstrate the ability to critically reflect on their practice with disabled people and the practice of others	<input type="checkbox"/>	<input type="checkbox"/>
7 Demonstrate the ability to actively and appropriately involve carers, personal assistants and/or advocates	<input type="checkbox"/>	<input type="checkbox"/>
8 Demonstrate an understanding of the power of language in regards to disability	<input type="checkbox"/>	<input type="checkbox"/>
9 Demonstrate an understanding of the social model of disability	<input type="checkbox"/>	<input type="checkbox"/>

* Please tick if the outcome is incorporated within disability equality teaching and learning in your institution

** Please tick if the outcome is incorporated within assessment in your institution



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