

A different perspective on...
DISABILITY EQUALITY

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Introduction

Ideas and Theory - Be prepared

While getting the welcome right is important, creating a deliberate invitation is fundamental. One in 10 people are disabled, so it's likely that many people using or working in your organisation are affected by some kind of impairment. However, only one in four disabled people are wheelchair users and since many impairments are hidden, you may be unaware that colleagues and service users are indeed disabled. There are a number of reasons for this: if impairments are generally unseen (such as epilepsy or depression) there would be no reason to share the information, so it is not in the public domain. Not all impairments are stigmatised or perceived as problematic¹⁶. For example, some people with visual impairments wear glasses but are not categorised as disabled. But where disabled people have been perceived and treated differently, or excluded from mainstream organisations, a social divide develops. Social exclusion and stigma means that many of us have not had the experience of a meaningful relationship with a disabled person and we may fear the unknown. For some people, interacting with disabled people may seem like a totally new experience.

Unfortunately, disability is generally viewed as a problem and disabled people face a social oppression. In other words, their daily experience is often more challenging than their non-disabled peers. In order to restore fairness and return those

who have been marginalised back to the daily lives of our communities and organisations, action is essential. This means deliberately inviting people back into the places where they may previously have felt uncomfortable or alienated. It demands that any discrimination must be addressed, allowing them a natural and ordinary experience. Many disabled people can still recall the pain of rejection, or the difficulty of having to 'fit in'.

The law says that harm is done when professionals fail to take the necessary steps to ensure that disabled people can access and participate fully in an organisation's activity.

The first step in getting this right is to take time to audit and plan our particular organisation's priorities. Then, once we expect diversity to come through door and are ready with a multitude of strategies to suit all types of individuals, we need to make sure people feel comfortable: giving them what they need is not the same as inviting them to join. As we will see later, for someone used to being excluded the offer needs to be positive and made with integrity. Asking disabled people to join in needs to involve a commitment to change those elements which may cause distress. Therefore a positive invite comes with a promise to listen! Belonging is everything here! Simply being in the room together is not enough. For people to feel they belong they need to feel part of the activity and the dialogue.

Furthermore, participation includes a sense of power, something which must be handed deliberately to those who have previously been denied it. It is as important for us to feel listened to as it is to actually get what we need: compromise is fine as long as the decision is shared.

The medical model of disability

The medical model of disability

The 'medical model' embodies the overriding cultural and historical response to disabled people. Although today some responses are less radical, segregation and cure still hold sway in our understanding. The model is one of deficit: it focuses on an individual's lack of ability and identifies medical intervention as the solution. Many organisations have traditionally been impairment-focused, led by non-disabled professionals employed to 'fix' the problem within the individual. They have provided specialist services and support which are often seen as an additional portions of pie given in an effort to compensate for personal tragedy. The medical model simply articulates the view of disabled people as passive receivers, 'the needy', sometimes worthy of extra benevolence and charity (see Fig. below).

If help can be provided in a mainstream setting without too much effort, then the individual may be integrated within the institution's terms. Otherwise, disabled people may be offered different options, such as specialist placement or isolation at home. All too often, the lack of understanding has led to abuse of freedom, denial of personal need and loss of dignity. Where expert power overrides family and professional judgement, clinicians have been given the right to make decisions in people's lives. Unfortunately, this can also affect areas in which they do not have appropriate expertise, such as schools, employment, housing and transport.

We have already considered the prevalent, negative and unhelpful media images of disabled people, but sometimes our professional language also lacks respect. Alas, people frequently confuse disability and illness, and use the two words as though they have the same meaning. However, they need to be understood as different. We cannot deny that the two are often linked but while illness is something we are all subject to at different times, being disabled is a reaction people face to their difference which may be a stable condition or the result of illness. The two meanings cannot be equated: illness is a personal matter while disability is in the public domain. Therefore, while a medical model of illness may indeed save a life, applying treatments or cures to other aspects of a disabled person's life makes little sense.

Yet confusion continues to permit medical categorisation and clinical intervention that amounts to an abuse of power in areas such as access to support, personal care, education, hous-

ing, and transport – areas which have little or nothing to do with medical matters. The extended power of some professionals in disabled people's lives can place great pressure on other priorities equally critical to wellbeing. For example, specialist appointments may leave little time for play, relationships and other life-building activities.

Families may struggle with the insensitive words and negative assumptions of those around them when illness or condition attracts inappropriate attention from others. As a family is subjected to the weight of a member's oppression, they experience the physical, systematic and attitudinal barriers by association. People who acquire impairments later in life face similar problems in coping. Not only may they have to deal with new personal difficulty, but they have to make sense of others' responses to their difference. For these reasons, coming to terms with different circumstances can for some people indeed represent a tragedy, as the experience can be extremely painful. While we cannot ignore this pain, we need to act publicly to address the issues in our own profession, including the behaviours and daily activity that impact negatively on disabled people. We need to acknowledge that additional suffering is primarily due to ignorance and a lack of access to 'ordinary' opportunities that others enjoy. The medical model's significance lies in its contrast between the personal and public domains. Disabled people may choose to share their personal and private matters although they cannot be made to: disclosure takes place most easily when supported by trusting relationships. The medical model must also be seen in balance,

contrasting with a social model of disability.

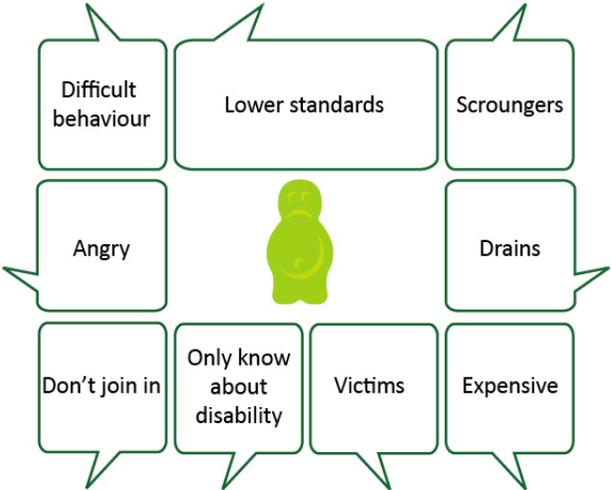
A language of shame

There is a great deal of confusion around the terminology relating to disability: indeed, people sometimes fear talking about it at all. The idea that disabled people are in some way 'faulty' lies at the heart of many stereotypes. The difference between political correctness and respectful language is one of ownership. Unfortunately, many people have imposed their ideas on the integration of disabled people: making decisions for others is patronising and erodes self-worth. Using language which is arbitrarily appointed as 'politically correct' is not necessarily appropriate and simply confuses issues. Language changes with ideas and there is no right or wrong word, just a present perspective. Using terms such as 'physically challenged', 'visually challenged', or 'with special needs', only serves to cement the deficit perspective. Crucially, such expressions also detract from the real issue: who is being challenged here? Many disabled people have no problem with their difference, but do feel challenged by other people's lack of acceptance and by the barriers they face. Working with disabled people demands compassion, not charity. A focus on social inequality can help restore personal value and acknowledges shared worth (note the direction of the speech bubbles in Fig below).

The medical model

The impairment is
The focus

The person is
percieved as
faulty.



SECTION 3

The social model of disability

Since the 1970s, groups of disabled people and political activists have argued that disability is a social construct.

Disability is the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities.

(Union of the Physically Impaired Against Segregation, 1976)

While this early definition is limited (it excludes people with hidden impairments), it emphasises that the organisation of society imposes an unfairness that actively disables. It focuses on the social response as the problem and therefore clearly contrasts with the medical model. It views segregation and the quest for a cure as the ideas that cause discrimination. Over the last sixty years, the Disability Movement has been an active force, catalysing the review and development of an ethically-focused route forward through community owner-

ship. The social model describes the way physical, systematic and attitudinal barriers fuel and perpetuate both the problem itself and the political strength of thousands who campaign for a change in society. The notion of ownership here is critical, as the shift in mindset concerns fundamental human rights. Disabled people face daily disadvantage because of the way our society is organised. The many examples of system inadequacy include:

- inaccessible work, leisure and public services
- inaccessible education systems
- barriers to participation
- inadequate disability benefits
- failure to take bullying seriously or prosecute unfair treatment.

The social model is not however confined to the physical environment. The need for social change is paramount and the onus rests with people, organisations, and communities to share ownership of the problem in order to remedy the situation. We need action to prevent the impact of prejudice on individuals who are no less entitled to contribute to their community than their non-disabled peers. Fear, ignorance and prejudice create barriers and discriminatory practices that actively disable. Understanding how discrimination is generated empowers everyone. It is also fundamental to a human rights approach.

The model also recognises that for many, impairment in a society that devalues disabled people and disabled lifestyles is often a personal tragedy. But the real tragedy is that our society, (and increasingly other societies too) continue to discriminate, exclude and oppress disabled people. (Ready, Willing and Disabled, Daone and Scott, Scope 2003)

The Disability Movement has attempted to move away from a personal tragedy theory, encouraging us instead to adopt a social theory of common responsibility. Many organisations such as People First and The Alliance for Inclusive Education operate nationally, and Centres for Inclusive Living and Action for Disabled People work locally to campaign for greater equality¹⁹. Regrettably, the impact remains limited as many charities still promote a cure perspective which reinforces victim status through pejorative ideas and imagery.

Non-disabled experts often work for disabled people, rather than with them. The move from integration to inclusion is not yet fully evident within these institutions. There is still pressure on disabled individuals to change, fit in or be grateful for the benevolence of the 'normal' person.

A language for change

Disability is not owned, it is imposed. Disabled people face an oppression called disablism that others do not face. Therefore it does not describe a personal characteristic but a widespread belief in the stereotypes we have already discussed. In this sense a disabled person is not a person with a disability, but a person with a difference or impairment who faces unfair treat-

ment from society as a result. The individual does not own the disability in the way that you might be 'a person with brown hair'. Consequently, the opposite of 'disabled' is not 'able-bodied' but 'non-disabled', meaning most people do not face disablism. Care needs to be taken to treat the illness category, ie the impairment, as different from the negative outcome of oppressive ideas.

Let's say that the person in figure below is Fred. According to the social model, Fred (the person) is a man with cerebral palsy (the impairment). When the barriers and discrimination (the oppression) that restrict Fred have been removed from society, Fred will still have cerebral palsy and he'll still be called Fred, but he will no longer be disabled.

Understanding the difference between these terms is key to resolving the medical model bias in existing language, and allows us all to talk clearly about:

- **the public:** a named individual = the person
- **the personal:** their impairment = their functioning
- **the cultural:** disablism = society's prejudice, including barriers, attitudes and ways of working.

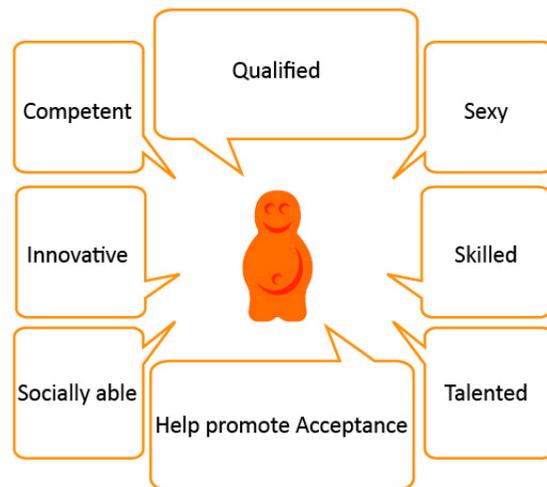
Examples of impairment: quadriplegia, polio, cerebral palsy, blindness, and depression.

Examples of disablism: Buildings without ramps, poor health provision, bullying, name-calling, segregated services and workplaces strategic vision ie. the social effects of oppression.

Please note however that the word disability remains a contested term internationally, with different individuals preferring people with disabilities to disabled people. If we are to use language to reflect the social model, the latter seems more respectful, while people with impairments may prefer the people first message.

The social model

Disable people are visible, equal members of the community and able to contribute to wider change.



Accommodation

A first step: accommodation

In order to reflect a social model approach it may be helpful to start by identifying the barriers disabled people face within our organisations. In the real world, the categories are rarely clear-cut but this task may help to extend thinking beyond the basics such as ramps and accessible toilets.

Compliance

Legislation such as the Disability Discrimination Act 1999 (updated in 2005) was enacted to protect disabled people from unfair treatment, but it still confused the personal and the public nature of the problem. The focus is the medical model, and definitions are largely about illness and lack of personal capacity.

Much of the literature regarding discrimination ignores the character of disablism altogether, and retains misleading language which reinforces a need for diagnosis. Sadly therefore, people still need clinical statements or doctors' certificates to support their needs or prove unlawful discrimination. Legislation tends to deal with improvement and reform, while the

law reinforces a need for personal remedy or adjustment it does little to tackle the source of stigma.

By definition, basic compliance is purely accommodation in an unfair culture. At best it is a short-term, individual and costly strategy which fails to address the deeper change required. More crucially, accommodation fails to tackle the sources of disablism. The law is weak, and evidence suggests that the few cases which get to trial are rarely won. The evidence on the number of disabled people gaining positions of authority is scant and SEN (Special Education Need) conferences still take place for which disabled people are possibly consulted but rarely involved. Policy and guidance continues to favour strategies based on remedial and interventionist treatment and few focus on the roots of a growing inequality.

Despite initial fears that the Single Equalities Act 2011 would dilute understanding, it has in fact stressed the need for systemic change. It places responsibility for change at boardroom level, with a requirement for evidencing the effects of business strategy and organisational purpose. But the case for real contribution to mainstream change is still in contention. Disabled people's views may still be ignored and their skills and insights may not be taken seriously in mainstream context.

Identify the barriers in your organisation

Physical

- 1.
- 2.
- 3.
- 4.
- 5.

Attitudinal

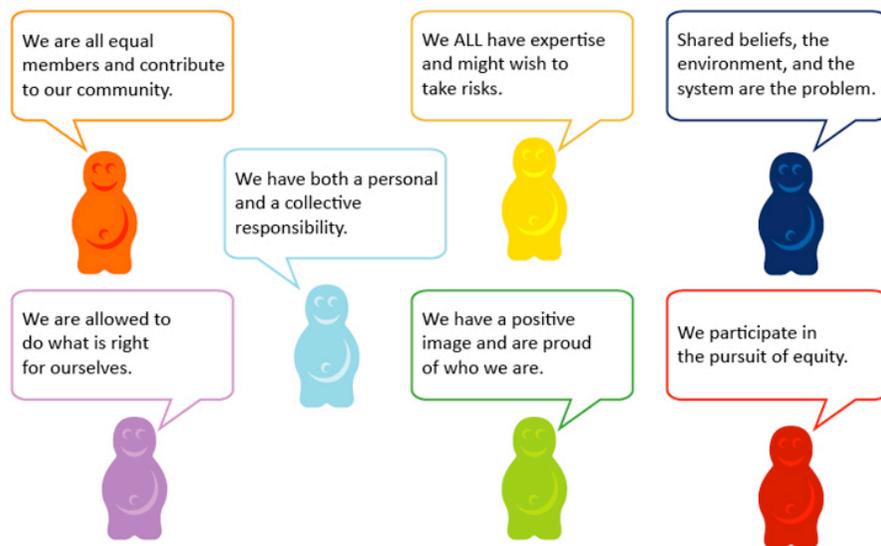
- 1.
- 2.
- 3.
- 4.
- 5.

Systemic

- 1.
- 2.
- 3.
- 4.
- 5.

Ethical commitment

A human rights approach



Ethical commitment

Disabled people frequently have to rely on the good nature, generosity and positive attitudes of enlightened individuals for the consideration which should be a universal right. This puts a conditional price on fairness and adds to the disabled population's growing stack of problems.

Firstly, opportunity is made conditional and there is all too often an underlying expectation of gratefulness in return. Unlike genuine thanks, having to be grateful for unfair measures can soon lead to a lack of self-respect and resentment. Secondly, it prevents the acknowledgement of an ethical imperative or a moral case for full entitlement to all human rights.

In this context, inclusive practice can be seen as the pursuit of equity, a deliberate movement towards ethical commitment in which it is understood that creating fairer opportunity requires action. It depends on a conviction that far-reaching change towards a greater vision can be achieved in a number of small but well chosen steps. Even when the vision is unclear, short-term goals can still be achieved, but the vision needs a moral purpose. It is just as important for groups to explore solutions through shared dialogue as it is to make detailed plans and set goals. Equality demands the respect of others: through meaningful relationships, dreams become reality and organisational communication and culture develop real meaning for all. Fulfilling relationships are essential to satisfy our need to belong and make sense of our participation: without them we have no reason to give. The degree to which we engage with our community is directly proportional to the quality of its interpersonal interactions. We gauge the worth of an organisation according to the welcome, acceptance and honesty of the individuals within it.

A human rights approach

From a human rights perspective, the fundamental issue remains that too many disabled people are still forced to make personal choices about 'fitting in' that would not be imposed on non-disabled people. To date, integration has been too conditional and many human rights are restricted in way that negatively affects the disabled population. None of the statements above are exclusive to any group: however the principles by which rights are made possible are not always equally extended to all.

Positive action

To address both the public nature of discrimination and the wider ranging aspects of unfairness within organisations, action must be planned. Not to be confused with positive discrimination (which is illegal), positive action constitutes a number of possible strategies for increasing fairness within your workplace. These strategies should address disabled people's needs in particular, while also addressing the causes of inequality and thus improving working practice for all.

Strength-based strategies and planning

Next few days

- 1.
- 2.
- 3.
- 4.

Next six weeks

- 1.
- 2.
- 3.
- 4.

In the next year

- 1.
- 2.
- 3.
- 4.

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