Reclaiming the Social Model of Disability

Conference Report

February 2000

Greater London Action on Disability (GLAD)

This report is available in print, large print, braille, on tape and on disk from GLAD at 336 Brixton Road, London SW9 7AA.
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Introduction

Greater London Action on Disability (GLAD) held the conference "Reclaiming the Social Model of Disability" in October 1999. GLAD held the conference to give disabled people a chance to talk about the Social Model. GLAD wanted to hear the views of a wide range of disabled people from different communities.

The social model of disability should be strong enough to take being talked about and even challenged. The most important thing is that it is *our* model, and that *all* disabled people, whatever our impairment, gender, race, age or whether we are a lesbian or gay man, can feel it is part of our lives, and feel that it empowers us.

Key points from the conference

❒	We need to produce an updated social model of disability that; includes a positive statement about us; recognises our diversity and difference; recognises institutionalised discrimination; talks about choice; recognises that not all the things that exclude us are about society's barriers; and talks about barriers (attitudes and access).

❒	We need to consult widely on this new definition.

❒	Once agreed, we need to publicise this model wider than the disability movement – and we need to do this in a way that is accessible to all, and make use of the internet.

❒	Labels say nothing about our experience as individuals, when they link us to a set of stereotypes. However, society uses labels as a short-hand, e.g. 'the homeless', 'single-parents', 'refugees', and so on.

❒	We need to challenge the portrayal of disabled people in the media, particularly the tabloid press and peak-time television shows.

❒	Disability organisations need to co-operate with each other – we need a collective voice.

Summary of the presentations

Jenny Morris, freelance researcher:

The social model of disability gives us the words to describe our experiences of inequality. It separates out disability (disabling barriers) from impairment (not being able to walk, or see or hear, or having difficulty learning).

There are two main types of disabling barriers. Attitudes (prejudice) and unequal access – the way in which society denies us access to the things we need to have a good quality life and to do the things that non-disabled people take for granted.

So my impairment is the fact that I can't walk; disability is the fact that architects think that steps are a wonderful design feature. Not being able to see is an impairment; disability is the failure to provide printed material on audio tape, in braille etc.

We use the word disability to mean oppression, to mean disabling barriers.

The social model doesn't deny the importance of impairment. It actually enables us to focus on our needs relating to impairment, because it means we can separate these out from the disabling barriers we experience.

The social model also doesn't deny our difference. We are different from non-disabled people for two reasons: we have needs arising from our impairments, and we experience disabling barriers of prejudice and unequal access.

This is why the government's recent advertising campaign ("See the Person") is so dangerous. We are asked to believe that it is progressive for non-disabled people to say to us, 'I don't see what makes your body or mind different from me, I just see you as a person'. This is not only an attempt to deny the feelings that people have about difference, it is also to deny that we *are* different – they deny the prejudice we experience, and deny the things we need to happen in order that we can have our human and civil rights.

The social model helps us to understand what needs to happen in order that we can access our human and civil rights.

But to have our human and civil rights, we also need entitlements to the additional things we require to have equal access: we need entitlements to physical access, to communication assistance, to personal assistance, to accessible information; we need legislation to protect us from prejudice.

We need human rights, civil rights and entitlements. These three statements illustrate the differences between these and the relationship between them:

'Disabled people have the right to be parents' *a human right*

'Disabled parents have the right to sit with their children in the cinema' *a civil right*
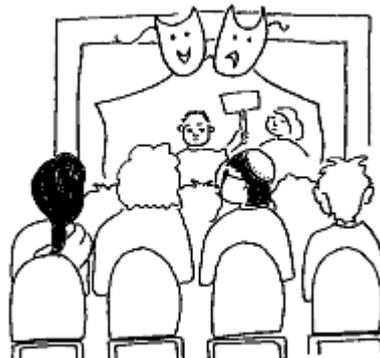
'Disabled parents have the right to assistance with looking after their children in their own homes if they need it' *an entitlement*

Because the social model separates out disabling barriers and impairments, it enables us to focus on exactly what it is which denies us our human and civil rights and what action needs to be taken in order to get us these rights. Sometimes the action is about removing disabling barriers, but sometimes it's about providing the help we need because of our impairment. Sometimes it's about being treated the same as everyone else, sometimes it's about being treated differently so that we can then achieve the same things as everyone else.

In the past our difference has only been recognised in a negative way, which has resulted in disabled people being segregated and excluded from society. The social model helps our difference to be acknowledged in a positive or neutral way and makes it more likely that we will get our human and civil rights.

Simone Aspis, freelance consultant:

The social model is based on the idea that disabled people will be able to access work and education equally if the environmental barriers are removed.

The learning difficulties label is given by schools to children when the school thinks the child is not learning as well as other children. The government tells schools how quickly a child must learn to do school work and be able to pass tests and what the child should learn.
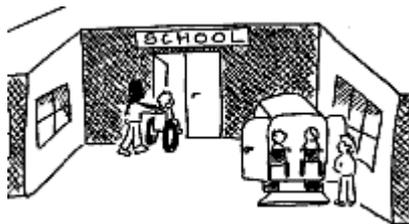
In our society intellectual ability is highly valued. Self reliance is encouraged as is standardisation rather than diversity. Value is placed on paid work, particularly of an intellectual rather than physical nature.
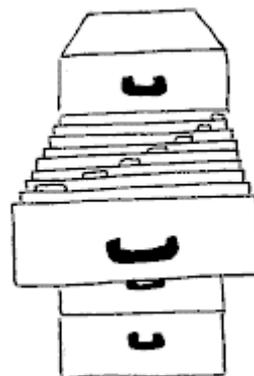
The medical model of disability sees the person as the problem, and the solution as making the person 'normal'. The medical model leads to the provision of special schools, special transport, sheltered jobs, physiotherapy and speech therapy, charities and benefits. It also leads to eugenics – getting rid of disabled babies by stopping disabled people and others having them.

The social model of disability sees society as the problem, and the solution as changing society. This means giving disabled people access to money, to personal assistance or support that we control, and to be able to work in a different way.

Nasa Begum, researcher and activist:

As mental health system survivors it is vital we claim the social model as a tool for understanding the discrimination and prejudice we face, and for helping to explain our experiences in society. You only have to spend two minutes with a mental health system survivor and you'll have the A to Z guide of disabling barriers.

Attitudinal barriers:
Images of people climbing into lion cages and murdering people is what the media immediately present you with; the presumption that if you hear voices, self harm or live life on a real roller coaster then you are not fit to make a decision about anything in your life; and of course there is the stigma associated with mental health problems.

Having a psychiatric record is much worse than having a criminal record, at least after you've been punished for a crime the conviction will usually be treated as 'spent' and something to be forgotten. However if you have a psychiatric record judgements are made about you for ever.

Environmental barriers:
If we accept the reality that many people's mental health problems are exacerbated by living in a stressful environment, then it is not difficult to think of environmental barriers which make worse, if not cause, mental health problems. For example, travelling on crowded public transport, rushing around, being confronted with racist, homophobic and sexist graffiti when you're going about your daily life or just simply not having a safe space to meet and talk with other people.

Institutional barriers:
Rather than providing preventative and out of hours support, we have legislation and institutions which take away our rights, deny us our freedom and strip away our dignity by putting us in locked wards where the regime of medication, television, smoking and occupational therapy is supposed to sort us out. In the name of care our fundamental human rights are denied and we are controlled by those who think they're fit to act as judge and jury.
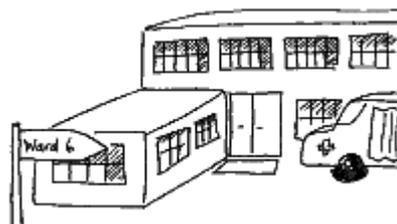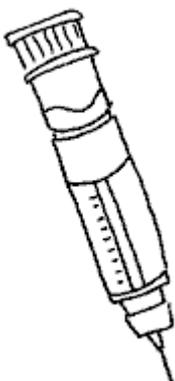
The proposals to introduce Community Treatment Orders and suggestions that certain people with so-called Personality Disorders be detained highlights how institutional barriers are being erected all the time, rather than being destroyed. Another example of institutional discrimination against mental health system survivors is the failure of the Disability Discrimination Act (DDA) to take mental health experiences on board properly. As you know the DDA is a major tool (although it doesn't go far enough) for addressing discrimination against disabled people, yet mental health system survivors have been tacked on in a very superficial and tokenistic way.

Although mental health system survivors face numerous barriers I would not want for a minute to deny or trivialise the fact that we have conditions which affect our lives. I believe the social model means we must understand disability as a form of social oppression like hetero-sexism, racism, sexism etc.

However we also have to have a safe place to talk about the reality of our conditions, after all you could try to remove as many barriers as possible but pain, hearing voices and feeling the need to self harm may still exist.

I know many of you are probably thinking I'm just pushing my own agenda and to some extent I would agree, but more importantly I believe the only way of properly addressing the rights of any group of people is to make ourselves inclusive and address all the diversity within our movement. This will be invaluable in terms of strengthening our campaign for full human and civil rights, and ensuring we have a representative and democratic movement.

For those of you wondering what on earth we could do about all this I will give you six hot tips to start the ball rolling:

☐ Like women have reclaimed the night, disabled people including mental health system survivors must reclaim the social model.

☐ Campaign and take practical action to ensure the social model of disability is understood and recognised as part of mental health system survivors experiences.

☐ Take action to tackle and challenge the attitudinal, environmental and institutional barriers mental health system survivors face.

☐ Ensure that the different communities, like mental health system survivors and the wider disability community take on and address their own prejudices and discrimination to build more inclusive and representative movements.

☐ Stop putting people into pigeon holes and recognise people come from a diverse range of communities and backgrounds. Therefore, Black disabled people (including mental health system survivors), disabled lesbians and gay men, disabled women and so on must be a central part of all the work within the individual and shared disability movements.

☐ Ensure legislation, policy, services, practice and campaigns apply the social model of disability to all disabled people, including those who face simultaneous oppression.
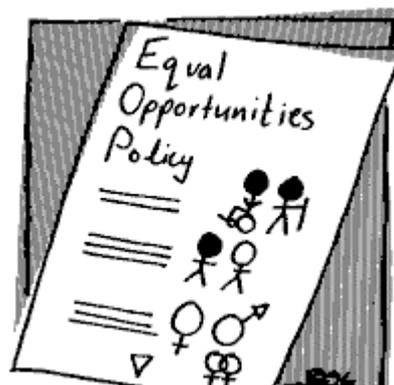
What people said in the workshops

The workshops took place in two parts. In the morning people talked about what the speakers had said. In the afternoon people agreed the key points they wanted to feedback to the conference.

The things that people said in the workshops are listed below. These are their words, not GLAD's. To make it easier we have used headings.

The definition of the Social Model of Disability:

- there is a lack of awareness amongst both disabled people and non-disabled people about what is the social model
- we're fed up with the exclusiveness of the social model – that only certain disabled people have the right to define it
- some mental health system survivors recognise the strength the social model gives the disability movement
- reclaiming the social model could be empowering – in the same way that the women's movement or lesbians and gay men have reclaimed language
- lots of organisations use the social model against disabled people because they have re-defined it to suit their purposes
- the word 'model' is difficult – should we say 'experience' instead because it's about our shared and individual experience?
- the definition needs to emphasise that it is exclusive practices that disable us, e.g. lack of accessible information
- the social/society part of the definition is fine, but the term impairment has medical model implications
- we need a more positive definition
- we need an acknowledgement of the medical, social and personal experience of being a disabled person, but non-disabled people can't separate out our personal experience from social or medical ones
- removing disabling barriers does not take away pain, or change our feelings – the social model needs to recognise this
- the social model is not the problem, it's the way it's being implemented

The language used, including the term 'impairment':

- language is important and people are never really happy with the words that are used – terms are used differently by different people and organisations
- 'survivor' is a good term, but not everyone has survived the system
- the problem with the social model for mental health system survivors is the idea of 'impairment'
- we're not sure if the term 'condition' is any better than 'impairment'
- 'impairment' is the medical model
- 'impairment' doesn't translate well into British Sign Language – it's a negative term
- using the term 'condition' may lead us to having to explain what our 'condition' is. It's still a medical way of defining our experience and it allows the medical system to label or mis-label us
- we need to ask who benefits from the language or terms used
- language can empower or dis-empower
- jargon excludes many people, particularly people with learning difficulties
- we need more inclusive language, e.g. "living with…" – we could learn from the language used by HIV/AIDS groups

Labels:

- there's a difficult balance between meeting needs and labelling or pigeon-holing people in order to do this
- people with hidden impairments often find it harder to get services
- deaf people may not accept the label 'disabled person' or 'disability'
- mental health system survivors often have to spend a lot of time arguing about what their condition or label is
- labels can be mis-leading or lead to discrimination depending on what label you are given
- it's not just the label, it's what's attached to it

The Medical Model:

- defining our symptoms or condition doesn't help us define the barriers we face
- ideas around 'capacity' (what people can and can't do) and who defines it are crucial
- there is a lack of acceptance of people's 'imperfections'

Equality and diversity:

- deaf people may have a different idea of what mental 'well-being' is
- mental health system survivors don't want the positive aspects of their experience dismissed
- lack of access is a big issue, including access to information and to transport
- we need unity in our diversity and in the oppression we experience
- we need acknowledgement of our rights and needs and to have these met, particularly around access
- equal opportunities means recognising that people start from different points or places
- other movements exclude disabled people, e.g. feminism

The media and images of disabled people:

- we shouldn't have to be 'super-human' to prove our worth or be noticed
- 'good' or 'normal' behaviour is rewarded – mental health system survivors are being asked to behave in a certain way in order to be included
- the focus on the individual rather than the collective experience is dangerous. For example, the government's "See the Person" campaign
- disabled people are not seen as sexual beings or as being able to have friendships, so it is assumed friends or lovers are carers
- children of disabled people experience discrimination
- disabled people aren't portrayed in the media doing everyday things - we need more positive role models and images of disabled people

- some charities add to the negative images of disabled people in order to raise money

The Disability Movement:

- choice of lifestyle is important, including the choice to be an activist or not, to work or not to work, etc – people have a right to choose not to be involved
- the amount of energy required to organise getting your needs met often means disabled people only have energy left for essential tasks
- disabled people need information in the format of their choice
- the issue of class needs to be taken on board by the disability movement
- there is a hierarchy of impairment developing in the movement
- disabled men are often oppressive
- the disability movement has its own barriers – e.g. the way it communicates using jargon, no pictures etc
- if you have difficulty communicating people don't listen to you
- people with hidden impairments need to be more involved in the movement
- there is a lack of awareness of other disabled people's needs, including access needs
- people may find it hard to speak up for what they need for fear it is seen as a weakness
- disabled people need disability equality training
- disabled people need to know what their rights are so that they can speak up and make their own decisions – information is power
- should the disability movement be campaigning for civil rights or human rights?
- The disability movement needs to 'sell' the social model, but first we need a definition that is inclusive, and in jargon-free language
- The leadership of the disability movement needs to be more open to debate and put ideas into action

Service providers:

- direct payments have discriminatory criteria
- services are structured in a particular way – they are not flexible
- disabled people can't get holiday insurance to cover existing conditions

Telling people what the social model is:

- service providers do not usually experience disabling barriers so they don't understand the social model
- non-disabled people often 'shut-off' when the social model is mentioned
- we need to get the government and others to sign up to <u>our</u> definition

A new definition?

The social model of disability describes the individual and shared experience that makes us disabled people.

'Disability' is the shared or common experience that disabled people have of discrimination and disabling barriers.

As individuals we may experience the discrimination and barriers differently, partly because we may also experience racism, homophobia and sexism. But what we experience in common is a lack of opportunity and disadvantage placed on us by society.

'Impairment' is the individual difference in our bodies, minds or the way we function which means we may have requirements or needs that must be met. If they are not met in a way that is right for us as individuals, this will add to the disadvantage we experience.

For disabled people to have equal access in society there must be a recognition of our *difference* as individuals and our *shared* experience of discrimination.

There must be an understanding that the different requirements relating to our impairment need to be met on an *individual* basis. There must be an understanding that our *shared* experience will only change if the negative attitudes of non-disabled people are changed and the physical and practical barriers in society as a whole are removed.

Conclusion

Feedback from the conference was very positive. Comments included:

"I had an excellent day – most inspiring"
"Brilliant conference – well done!"

The fact that the conference was fully booked, with people on the reserve list, highlights the level of interest in discussing the social model of disability.

The social model of disability should include every disabled person – in the past it was defined by a small group of articulate disabled people with particular impairments.

Action for GLAD

1. Produce a report of the conference, that is jargon-free, with pictures and launch it with a lead article in London Disability News. Seek coverage from other disability press.

2. Produce a short guide describing the social model and talking about language. Consult on this. Once it's agreed distribute it widely – not just to disability groups.

Further Information

Full copies of Simone Aspis, Nasa Begum and Jenny Morris's presentations are available from GLAD, in print or on tape.
The pictures used in this report are from CHANGE's "Picture Bank". This is a CD-Rom and book available from CHANGE, 69-85 Old Street, London EC1V 9HY. Tel: 020 7490 2668, Fax: 020 7490 3581, Textphone: 020 7490 3483.

People we'd like to say 'thank you' to

GLAD would like to thank the following people for their role in the conference:

- All the people who came to the conference
- The speakers – Simone Aspis, Nasa Begum and Jenny Morris
- The workshop facilitators – Nasa Begum, Brenda Ellis and Karen Edmunds
- Carol Uszkurat and Susanna Hancock for chairing the conference
- GLAD staff and volunteers who helped with the organising, taking notes, taking photos etc, including Barbara Zipser, Alison Julal, Ju Gosling, Tim Leech, Atique Khan, Jenny Nathan and Eric Abrahams.

Karen Edmunds
Director