

# Including All of Our Lives: Renewing the social model of disability

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[This chapter has its origins in an article written for Coalition - one of the journals of the British disabled people's movement. In the four years since it appeared in that initial form, both discussions with other disabled people and my own circumstances have influenced my thinking. During that time, we have started to talk more freely about our experiences of impairment and the more fully developed form of the social model of disability that is advocated here is already beginning to be applied informally within the disabled people's movement.]

My life has two phases: before the social model of disability, and after it. Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it.

This was the explanation I had sought for years. Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live.

I was being dis-abled - my capabilities and opportunities were being restricted - by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary!

For years now this social model of disability has enabled me to confront, survive and even surmount countless situations of exclusion and discrimination. It has been my mainstay, as it has been for the wider disabled people's movement. It has enabled a vision of ourselves free from the constraints of disability (oppression) and provided a direction for our commitment to social change. It has played a central role in promoting disabled people's individual self-worth, collective identity and political organisation. I don't think it is an exaggeration to say that the social model has saved lives. Gradually, very gradually, its sphere is extending beyond our movement to influence policy and practice in the mainstream. The contribution of the social model of disability, now and in the future, to achieving equal rights for disabled people is incalculable.

So how is it that, suddenly, to me, for all its strengths and relevance, the social model doesn't seem so water-tight anymore? It is with trepidation that I criticise it. However, when personal experience no longer matches current explanations, then it is time to question afresh.

## **Disability is 'all'?**

The social model of disability has been our key to dismantling the traditional conception of impairment<sup>1</sup> as 'personal tragedy' and the oppression that this creates.

Mainstream explanations have centred on impairment as 'all' - impairment as the cause of our experiences and disadvantage, and impairment as the focus of intervention. The World Health Organisation defines impairment and related concepts as follows:

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function. Disability: Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents fulfilment of a role that is normal, depending on age, sex, social or cultural factors for that individual. (United Nations Division for Economic and Social Information, 1983, p.3)

Within this framework, which is often called the medical model of disability, a person's functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure.

The social model, in contrast, shifts the focus from impairment onto disability, using this term to refer to disabling social, environmental and attitudinal barriers rather than lack of ability. Thus, while impairment is the functional limitation(s) which affect a person's body, disability is the loss or limitation of opportunities resulting from direct and indirect discrimination. Social change - the removal of disabling barriers - is the solution to the disadvantages we experience. This way of seeing things opens up opportunities for the eradication of prejudice and discrimination.

In contrast, the medical model makes the removal of disadvantage contingent upon the removal or 'overcoming' of impairment - full participation in society is only to be found through cure or fortitude. Small wonder, therefore, that we have focused so strongly on the importance of disabling barriers and struggled to dismantle them.

In doing so, however, we have tended to centre on disability as 'all'. Sometimes it feels as if this focus is so absolute that we are in danger of assuming that impairment has no part at all in determining our experiences. Instead of tackling the contradictions and complexities of our experiences head on, we have chosen in our campaigns to present impairment as irrelevant, neutral and, sometimes, positive, but never, ever as the quandary it really is.

Why has impairment been so excluded from our analysis? Do we believe that admitting there could be a difficult side to impairment will undermine the strong, positive (SuperCrip?) images of our campaigns? Or that showing every single problem cannot be solved by social change will inhibit or excuse non-disabled people from tackling anything at all? Or that we may make the issues so complex that people feel

constructive change is outside their grasp? Or even that admitting it can sometimes be awful to have impairments may fuel the belief that our lives are not worth living?

### **Bring back impairment!**

The experience of impairment is not always irrelevant, neutral or positive. How can it be when it is the very reason used to justify the oppression we are battling against? How can it be when pain, fatigue, depression and chronic illness are constant facts of life for many of us?

We align ourselves with other civil rights movements and we have learnt much from those campaigns. But, we have one fundamental difference from other movements, which we cannot afford to ignore. There is nothing inherently unpleasant or difficult about other groups' embodiment: sexuality, sex and skin colour are neutral facts. In contrast, impairment means our experiences of our bodies can be unpleasant or difficult. This does not mean our campaigns against disability are any less vital than those against heterosexism, sexism or racism; it does mean that for many disabled people personal struggle related to impairment will remain even when disabling barriers no longer exist.

Yet our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment. Impairment is safer not mentioned at all.

This silence prevents us from dealing effectively with the difficult aspects of impairment. Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realising our potential or railing fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments; we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments. Yet our silence about impairment has made many of these things taboo and created a whole new series of constraints on our self-expression.

Of course, the suppression of concerns related to impairment does not mean they cease to exist or suddenly become more bearable. Instead this silencing undermines individuals' power to 'cope' and, ultimately, the whole disabled people's movement. As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence so much of our lives. External disabling barriers may create social and economic disadvantage but our subjective experience of our bodies is also an integral part of our everyday reality. What we need is to find a way to integrate impairment into our whole experience and sense of our selves for the sake of our own physical and emotional well-being, and, subsequently, for our individual and collective capacity to work against disability.

As a movement, we need to be informed about disability and impairment in all their diversity if our campaigns are to be open to all disabled people. Many people find that it is their experience of their bodies - and not only disabling barriers such as inaccessible public transport - which make political involvement difficult. For example, an individual's capacity to attend meetings and events might be restricted because of limited energy. If these circumstances remain unacknowledged, then alternative ways of contributing are unlikely to be sought. If our structures and strategies - how we organise and offer support in our debates, consultation and demonstrations - cannot involve all disabled people, then our campaigns lose the contributions of many people. If our movement excludes many disabled people or refuses to discuss certain issues then our understanding is partial: our collective ability to conceive of, and achieve, a world which does not disable is diminished. What we risk is a world which includes an 'elite' of people with impairments, but which for many more of us contains no real promise of civil rights, equality or belonging. How can we expect anyone to take seriously a 'radical' movement which replicates some of the worst exclusionary aspects of the society it purports to change?

Our current approach to the social model is the ultimate irony: in tackling only one side of our situation we disable ourselves.

### **Redefining impairment**

Our fears about acknowledging the implications of impairment are quite justified. Dominant perceptions of impairment as personal tragedy are regularly used to undermine the work of the disabled people's movement and they rarely coincide with disabled people's understandings of their circumstances. They are individualistic interpretations: our experiences are entirely explained by each individual's psychological or biological characteristics. Any problems we encounter are explained by personal inadequacy or functional limitation, to the exclusion of social influences.

These interpretations impose narrow assumptions about the varying experiences of impairment and isolate experience from its disabling context. They also segregate us from each other and from people without impairments. Interpreting impairment as personal tragedy creates fear of impairment and an emphasis on medical intervention. Such an interpretation is a key part of the attitudes and actions that disable us.

However, the perception of impairment as personal tragedy is merely a social construction; it is not an inevitable way of thinking about impairment. Recognising the importance of impairment for us does not mean that we have to take on the non-disabled world's ways of interpreting our experience of our bodies.

In fact, impairment, at its most basic level, is a purely objective concept which carries no intrinsic meaning. Impairment simply means that aspects of a person's body do not function or they function with difficulty. Frequently this is taken a stage further to imply that the person's body, and ultimately the person, is inferior. However, the first is fact; the second is interpretation. If these interpretations are socially created then they are not fixed or inevitable and it is possible to replace them with alternative interpretations based on our own experience of impairment.

This self-interpretation add a whole new layer of personal, subjective interpretations to the objective concept of impairment. The personal interpretation incorporates any meaning that impairment holds for an individual (i.e. any effects it has on their activities), the feelings it produces (e.g. pain) and any concerns the individual might have (e.g. how their impairment might progress). Individuals might regard their impairment as positive, neutral or negative, and this might differ according to time and changing circumstances.

With this approach, the experiences and history of our impairments become a part of our autobiography. They join our experience of disability and other aspects of our lives to form a complete sense of ourselves.

Acknowledging the relevance of impairment is essential to ensuring that people are knowledgeable about their own circumstances. An individual's familiarity with how their body works allows them to identify their specific needs. This is a precursor to meeting those needs by accessing existing information and resources. Self-knowledge is the first stage of empowerment and gives a strong base for individuals to work collectively to confront disability and its impact upon people with impairments.

We need to think about impairment in three, related, ways:

- First, there is the objective concept of *impairment*. This was agreed in 1976 by the Union of Physically Impaired Against Segregation (UPIAS, 1976) and has since been developed by Disabled People's International (DPI) to include people with a range of non-physical impairments:

Impairment: lacking all or part of a limb, or having a defective limb, organism or mechanism of the body.

- Second, there is the individual interpretation of the *subjective experience of impairment* in which an individual binds their own meanings to the definition of impairment to convey their personal circumstances.
- Finally, there is the impact of the wider *social context* upon impairment, in which misrepresentation, social exclusion and discrimination combine to disable people with impairments.

It is this third aspect to impairment which is not inevitable and its removal is the primary focus of the disabled people's movement. However, all three layers are currently essential to an understanding of our personal and social experiences.

### **Responses to impairment**

We need to reclaim and acknowledge our personal experiences of impairment in order to develop our key debates, to incorporate this experience into the wider social context and target any action more precisely. One critical area of concern is the different responses to impairment, for ultimately these determine our exclusion or inclusion.

Currently, the main responses to impairment divide into four broad categories:

- avoidance/'escape', through abortion, sterilisation, withholding treatment from Disabled babies, infanticide and euthanasia (medically assisted suicide) or suicide.
- management, in which any difficult effects of impairment are minimised and incorporated into our individual lives, without any significant change in the impairment.
- cure through medical intervention
- prevention, including vaccination, health education and improved social conditions

The specific treatments that emerge from these responses differ markedly according to whether they are based on the medical or social model. Currently, the treatment available is dominated by the medical model's individualistic interpretation of impairment as tragic and problematic and the sole cause of disadvantage and difficulty.

This leads policy-makers and professionals to seek a 'solution' through the removal of impairment. Each of these responses is considered, at different times and in different contexts, to be valuable in bringing about the perceived desired outcome of reducing the number of people with impairments. The result is often a fundamental undermining of our civil and human rights.

For example, although not currently legal in Britain, euthanasia and infanticide are widely advocated where the 'quality of life' of someone with an impairment is deemed unacceptably low. An increasing number of infanticide and euthanasia cases have reached the courts in recent years, with judgements and public responses implying increasing approval. Infanticide is justified on grounds that 'killing a defective infant is not morally equivalent to killing a person. Very often it is not wrong at all'. Suicide amongst people with impairments is frequently considered far more rational than in people without, as though impairment renders it the obvious, even the only, route to take. Ruth Bailey's chapter has illustrated how assumptions of the inevitable poor quality of life with an impairment dominate the development of prenatal screening and abortion. These approaches have created a huge research industry and foetal screening and abortion are now major users of impairment-related resources.

Prevention of impairment through public health measures receives only minimal consideration and resourcing. The isolation of impairment from its social context means the social and economic causes of impairment often go unrecognised. The definitions of prevention are also questionable, in that foetal screening and subsequent abortion are categorised by mainstream approaches as preventative, whereas in reality such action is about the elimination of impairment.

Where removal of impairment is not possible, mainstream approaches extend to the management of impairment, although this remains one of the most under-resourced areas of the health service. However, much of the work in this area, rather than increasing an individual's access to and control over the help that they might need, is

more about disguising or concealing impairment. Huge amounts of energy and resources are spent by medical and rehabilitation services to achieve this. For example, many individuals are prescribed cosmetic surgery and prostheses which have no practical function and may actually inhibit an individual's use of their body. Others are taught to struggle for hours to dress themselves when the provision of personal assistance would be more effective.

There are a number of critical flaws in mainstream interpretations of impairment and associated interventions. First, little distinction is made between different people's experience of impairment or different aspects of a single impairment - or indeed, whether there may be positive aspects to some impairments. Instead, resources are applied in a generalised way to end impairment, regardless of the actual experience and interpretations of the people concerned. With the development of genetic screening, intervention aims to eliminate people with specific types of impairment altogether. Rarely is consideration given to the positive attributes of impairment. For example, the cystic fibrosis gene confers resistance to cholera which is an important benefit in some parts of the world. Associations are being identified between some impairments and creative or intellectual talent, while impairment in itself requires the development of more co-operative and communitarian ways of working and living - an advantage in a society with so much conflict to resolve.

Second, impairment is presented as the full explanation, with no recognition of disability. Massive resources are directed into impairment-related research and interventions. In contrast, scant resources are channelled into social change for the inclusion of people with impairments. For example, research will strive to 'cure' an individual of their walking difficulty, whilst ignoring the social factors which make not walking into a problem. There is little public questioning of the distribution of funds between these two approaches. Additionally, such assumptions inhibit many disabled people from recognising the true causes of their circumstances and initiating appropriate responses.

A third criticism is that, while these responses to impairment are seen as representing the interests of disabled people, they are made largely by people with no direct experience of impairment, yet are presented as authoritative. Disabled people's knowledge, in contrast, is frequently derided as emotional and therefore lacking validity<sup>2</sup>. Although mainstream interventions are presented as being for the benefit of disabled people, in fact they are made for a non-disabled society. Ingrained assumptions and official directives make it clear that there is an implicit, and sometimes explicit, intention of population control. Abortion, euthanasia and cure are presented as 'quality of life' issues, but are also justified in terms of economic savings or 'improvement' to populations<sup>3</sup>.

It is counteracting these and related concerns which motivates the disabled people's movement. The social model of disability rejects the notion of impairment as problematic, focusing instead on discrimination as the key obstacle to a disabled person's quality of living. The logical extension of this approach is to seek a solution through the removal of disability and this is what the disabled people's movement

works towards.

As a result, the overriding emphasis of the disabled people's movement is on social change to end discrimination against people with impairments. There is a strong resistance to considering impairment as relevant to our political analysis. When impairment is discussed at all within the disabled people's movement it tends to be in the context of criticising mainstream responses. We have, for example, clearly stated that foetal screening for abortion and the implicit acceptance of infanticide for babies with significant impairments are based on assumptions that our lives are not worth living. Our intervention in public debates in recent years about medically assisted suicide (euthanasia) has exposed the same assumption. In contrast, we have asserted the value of our lives and the importance of external disabling barriers, rather than impairment in itself, in determining quality of life. The same perspective informs our criticisms of the resources spent on attempting to 'cure' people of their impairments.

It is this rejection of impairment as problematic, however, that is the social model's flaw. Although social factors do generally dominate in determining experience and quality of life - for example requests for euthanasia are more likely to be motivated by lack of appropriate assistance than pain (Seale and Addington Hall, 1994) - impairment is relevant. For fear of appearing to endorse mainstream interpretation, we are in danger of failing to acknowledge that for some individuals impairment - as well as disability - causes disadvantage.

Not acknowledging impairment also lays the disabled people's movement open to misappropriation and misinterpretation. For example, disabled people's concerns about genetic screening and euthanasia have been used by 'pro-life' groups to strengthen their arguments. Equally, the movement's rejection of medical and rehabilitation professionals' approaches to treatment and cure has not been accompanied by an exploration of what forms of intervention would be useful. Our message tends to come across as rejecting all forms of intervention when it is clear that some interventions, such as the alleviation of pain, in fact require more attention and resources. In both cases, the reluctance of the disabled people's movement to address the full implications of impairment leaves its stance ambiguous and open to misuse.

It is also clear that, by refusing to discuss impairment, we are failing to acknowledge the subjective reality of many disabled people's daily lives. Impairment is problematic for many people who experience pain, illness, shortened lifespan or other factors. As a result, they may seek treatment to minimise these consequences and, in extreme circumstances, may no longer wish to live. It is vital not to assume that they are experiencing a kind of 'false consciousness' - that if all the external disabling barriers were removed they would no longer feel like this. We need to ensure the availability of all the support and resources that an individual might need, whilst acknowledging that impairment can still be intolerable.

This does not imply that all impairment is intolerable, or that impairment causes all related disadvantage; nor does it negate the urgency with which disability must be confronted and removed. It simply allows us, alongside wider social and political

change, to recognise people's experiences of their bodies. Without incorporating a renewed approach to impairment we cannot achieve this.

### ***A renewed social model of disability***

We need to take a fresh look at the social model of disability and learn to integrate all its complexities. It is critical that we recognise the ways in which disability and impairment work together. The social model has never suggested that disability represents the total explanation or that impairment doesn't count - that has simply been the impression we have given by keeping our experiences of impairment private and failing to incorporate them into our public political analysis.

We need to focus on disability and impairment: on the external and internal constituents they bring to our experiences. Impairment is about our bodies' ways of working and any implications that holds for our lives. Disability is about the reaction and impact of the outside world on our particular bodies. One cannot be fully understood without attention to the other, because whilst they can exist independently of each other, there are also circumstances where they interact. And whilst there are common strands to the way they operate, the balance between disability and impairment, their impact and the explanations of their cause and effect will vary according to each individual's situation and from time to time.

We need a renewed social model of disability. This model would operate on two levels: a more complete understanding of disability and impairment as social concepts; and a recognition of an individual's experiences of their body over time and in variable circumstances. This social model of disability is thus a means to encapsulating the total experience of both disability and impairment.

Our current approach is based primarily on the idea that once the struggle against disability is complete, only the impairment will remain for the individual and there will be no disadvantage associated with this. In other words, when disability comes to an end there will be no socially-created barriers to transport, housing, education and so on for people with impairments. Impairment will not then be used as a pretext for excluding people from society. People with impairments will be able to participate in and contribute to society on a par with people who do not have impairments.

In this non-disabling society, however, impairment may well be unaltered and some individuals will find that disadvantages remain. Removal of disability does not necessarily mean the removal of restricted opportunities. For example, limitations to an individual's health and energy levels or their experience of pain may constrain their participation in activities. Impairment in itself can be a negative, painful experience.

Moreover, whilst an end to disability means people with impairments will no longer be discriminated against on those grounds, they may remain disadvantaged in their social and economic opportunities by the long-term effects of earlier discrimination. Although affirmative action is an important factor in alleviating this, it is unlikely to be able to undo the full scale of discrimination for everyone.

Our current interpretation of the social model also tends to assume that if impairment ceases, then the individual will no longer experience disability. In practice, however, they may continue to be disabled, albeit to a lesser degree than previously. Future employment opportunities, for example, are likely to be affected by past discrimination in education even when impairment no longer exists.

In addition, an end to impairment may also trigger a massive upheaval to those aspects of an individual's self-identity and image formed in response to disability and impairment. It can also signal the loss of what may be an individual's primary community. These personal and collective identities are formed in response to disability. That further changes may be required in changing circumstances is a sign of the continuing legacy of disability.

Our current approach also misses the fact that people can be disabled even when they have no impairment. Genetic and viral testing is now widely used to predict the probability of an individual subsequently acquiring a particular impairment. Fear has been expressed that predisposition to impairment will be used as a basis for discrimination, particularly in financial and medical services.

There are also circumstances in which disability and impairment exist independently, and change in one is not necessarily linked to change in the other. For example, disability can dramatically ease or worsen with changes to an individual's environment or activities even when their particular impairment is static. Leaving a purpose-built home to go on holiday, for example, may give rise to a range of access restrictions not usually encountered, even though an individual's impairment remains the same. Equally, an employee with an impairment may find their capacity to succeed at work is confounded within one organisation but fully possible in another simply because of differences in the organisations' equality practices.

Where impairment increases, disability does not necessarily follow suit if adequate and appropriate resources are readily available to meet changes in need. A new impairment, a condition which fluctuates or a progressive impairment may mean that an individual needs additional or changing levels of personal assistance, but disability will remain constant if that resource is easily accessed, appropriate and flexible.

Perhaps most importantly, however, disability and impairment interact. Impairment must be present in the first instance for disability to be triggered: disability is the form of discrimination that acts specifically against people with (or who have had) impairments. This does not mean that impairment causes disability, but that it is a precondition for that particular oppression.

However, the difficulties associated with a particular impairment can influence the degree to which disability causes disadvantage. For example, an individual with a chronic illness may have periods in which their contact with the social world is curtailed to such an extreme that external restrictions become irrelevant. At times of improved health the balance between impairment and disability may shift, with opportunities lost

through discrimination being paramount.

Impairment can also be caused or compounded by disability. An excessively steep ramp, for example, might cause new impairment or exacerbate pain. An inaccessible health centre can restrict the availability of health screening that would otherwise prevent certain impairments, whilst inadequate resourcing can mean that pain reduction or management techniques are not available to many of the people who need them. Medical treatments, including those used primarily for cosmetic purposes, can cause impairment - for example, it has now emerged that a 'side effect' of growth hormone treatment is the fatal Creutzfeldt-Jakob Disease.

Discrimination in general can also cause major emotional stress and place mental health at risk. Our reluctance to discuss impairment obscures this aspect of disability. If we present impairment as irrelevant then, even where impairment is caused by disability, it is, by implication, not a problem. This limits our ability to tackle social causes of impairment and so diminishes our campaigns.

Like disability, other inequalities can also create or increase impairment. For example, abuse associated with racism or heterosexism, sexist pressure to modify physical appearance and lack of basic provision because of poverty can all lead to impairment. A significant proportion of people become active in the disabled people's movement as a result of such experiences, or through a recognition of these (and other) links that exist between oppressions.

Different social groups can also experience diverse patterns of impairment for a variety of social and biological reasons. Impairment for women, for example, is more likely to be associated with chronic pain, illness and old age (Morris, 1994). Excluding the implications of impairment risks reducing the relevance of the social model of disability to certain social groups. For example, the most common cause of impairment amongst women is the chronic condition, arthritis, where the major manifestation of impairment is pain. Unless the social model of disability incorporates a recognition of the patterns of impairment experienced by different social groups, there will be a failure to develop appropriate services.

Impairment can also be influenced by other external factors, not necessarily discriminatory, which may be physical, psychological or behavioural. Differences in cultural and individual approaches to pain and illness, for example, can significantly affect the way a person feels, perceives and reacts to pain. The study of pain control has revealed that pain can be significantly reduced by a range of measures, including by assisting individuals to control their own treatment programmes and through altered mental states associated with meditation or concentration in activity. The limited availability of such measures to many people who could benefit extends this to the sphere of disability.

Social factors can, at the most fundamental level, define what is perceived as impairment. Perceptions of norms and differences vary culturally and historically. As mainstream perceptions change, people are defined in and out of impairment. Many

people labelled 'mentally ill', for example, simply do not conform to contemporary social norms of behaviour. Other inequalities may contribute to the identification of impairment. For example, racist classifications in the school psychological service have led to a disproportionately high number of Black compared to white children in segregated units for 'the emotionally and behaviourally disturbed', whilst it is relatively recently that the sexuality of lesbians and gay men has ceased to be officially defined as 'mental illness'.

Mainstream perceptions tend to increase the boundaries of impairment. The logical outcome of a successful disabled people's movement is a reduction in who is perceived as having an impairment. An absence of disability includes the widespread acceptance of individuality, through the development of a new norm which carries an expectation that there will be a wide range of attributes within a population. With an end to disability, many people currently defined as having an impairment will be within that norm. Impairment will only need definition as such if in itself it results in disadvantages such as pain, illness or reduced opportunities.

### **Conclusion**

I share the concerns expressed by some disabled people that some of the arguments I have put forward here could be used out of context to support the medical model of disability, to support the view that the experience of impairment is nothing but personal tragedy. However, suppression of our subjective experiences of impairment is not the answer to dealing with these risks; engaging with the debates and probing deeper for greater clarity might well be.

I am arguing for a recognition of the implications of impairment. I am not supporting traditional perspectives on disability and impairment, nor am I advocating any lessening of the energies we devote to eliminating disability. Acknowledging our personal experiences of impairment does not in any way disregard the tremendous weight of oppression, nor does it undermine our alignment with other civil rights movements. Certainly, it should not weaken our resolve for change. Disability remains our primary concern, and impairment exists alongside.

Integrating those key factors into our use of the social model is vital if we are to understand fully the ways that disability and impairment operate. What this renewed social model of disability does is broaden and strengthen the current social model, taking it beyond grand theory and into real life, because it allows us to incorporate a holistic understanding of our experiences and potential for change. This understanding needs to influence the structure of our movement - how we organise and campaign, how we include and support each other. A renewed approach to the social model is vital, both individually and collectively, if we are to develop truly effective strategies to manage our impairments and to confront disability. It is our learning and support within our own self-advocacy and political groups, peer counselling, training and arts that enable us to confront the difficulties we face, from both disability and impairment. It is this that allows us to continue working in the most effective way towards the basic principle of equality that underpins the disabled people's movement.

It is this confronting of disability and aspects of impairment that underpins the notion of disability pride which has become so central to our movement. Our pride comes not from 'being disabled' or 'having an impairment' but out of our response to that. We are proud of the way we have developed an understanding of the oppression we experience, of our work against discrimination and prejudice, of the way we live with our impairments.

A renewed approach to the social model is also relevant in our work with non-disabled people, particularly in disability equality training. Most of us who run such courses have avoided acknowledging impairment in our work, concerned that it confirms stereotypes of the 'tragedy' of impairment or makes the issues too complicated to convey. Denying the relevance of impairment, however, simply does not ring true to many non-disabled people: if pain, by definition, hurts then how can it be disregarded? We need to be honest about the experiences of impairment, without underplaying the overwhelming scale of disability. This does not mean portraying impairment as a total explanation, presenting participants with medical information or asking them to fantasise impairment through 'experiential' exercises. Instead, it allows a clear distinction to be made between disability and impairment, with an emphasis on tackling disabling barriers.

The assertion of the disabled people's movement that our civil and human rights must be protected and promoted by the removal of the disabling barriers of discrimination and prejudice has gained significant public support in recent years. It is this social model of disability which underpins the civil rights legislation for which we campaign, and civil rights will remain the centre of our political attention.

At a time when so many people - disabled and non-disabled - are meeting these ideas afresh, we need to be absolutely clear about the distinction between disability and impairment. The onus will remain upon disabled people to prove discrimination and there will still be attempts to refute our claims by using traditional perceptions of impairment. To strengthen our arguments we must peel away the layers and understand the complexities of the way disability and impairment work so that our allegations of discrimination are water-tight. This is necessary now in our campaigning for full civil rights and will remain necessary when we claim justice under the legislation which will inevitably follow that campaign.

At this crossroads in disabled people's history, it is time for this renewed approach to the social model and the way we apply it. Disability is still socially created, still unacceptable, and still there to be changed; but by bringing impairment into our total understanding, by fully recognising our subjective experiences, we will achieve the best route to that change, the only route to a future which includes us all.

## **Notes**

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1. Along with many disabled people, I feel some discomfort at the word impairment because it has become so imbued with offensive interpretation. Perhaps we need to replace impairment with an alternative term.

2. For example, a medical law committee drawing up recommendations for withdrawing treatment from newborn babies with impairments specifically excluded disabled adults or the parents of disabled children from the committee because 'the emotional discussion, which might have been likely, would have been very unhelpful and even counterproductive to the matter on hand', Prof Dr med. H.D. Hiersche in his introductory speech to the German Association of Medical Law on 'Limits On the Obligation to Treat Severely Handicapped Newborns', 27-29 June, 1986.

3. A new screening test for Down's Syndrome is recommended for all pregnant women on the grounds that the £88 test will reduce the cost per 'case' discovered (and, presumably, aborted) from the current £43,000 to £29,500. See *Pulse*, 25 May, 1991.

In an unpublished paper, a philosopher at Saarbrücken University in Germany used

economic decision theory to quantify the value of life, including measuring which people should be subjected to involuntary euthanasia ('euthanasees'). Reported by Wilma Kobusch in a press statement, Gelenkirchen, 5 November, 1991.