

Impairment and disability: constructing an ethics of care
which promotes human rights

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***(Penultimate draft of article published in Hypatia, Vol. 16, No. 4,
Fall 2001).***

The social model of disability gives us the tools not only to challenge the discrimination and prejudice we face, but also to articulate the personal experience of impairment. Recognition of difference is therefore a key part of the assertion of our common humanity and of an ethics of care which promotes our human rights.

INTRODUCTION

When I became disabled, 17 years ago, I had already experienced a decade of feminism. Throughout my 20's I had been able to articulate my personal experiences of oppression through the politics of the women's movement. However, at the age of 33, when I was plummeted into a new experience of social exclusion, I soon realised that there had been little room for disabled women within either feminist ideas or the women's movement. I was extremely lucky that the disabled people's movement in Britain was gathering strength from the early 1980s and it gave me a political perspective with which to understand my personal experience. It has also given me the foundation stones of the analysis and the values I bring to the research I do.

The cornerstone of this foundation is the recognition that the language we use is central to the way we interpret our experiences.

THE SOCIAL MODEL OF DISABILITY

The central plank of the way I now see the world is evident in my use of the term "disabled women" rather than "women with disabilities". To put it in a nutshell, the disabled people's movement in Britain doesn't use the term "disability" to mean impairment but to refer to the disabling barriers of prejudice, discrimination and social exclusion. The British Council of Disabled People has adopted the following definitions:

Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. (Therefore, *disability*, like racism or sexism, is discrimination and social oppression).

Impairment is a characteristic, feature or attribute within an individual which is long term and may or may not be the result of disease or injury and may

1. affect that individual's appearance in a way which is not acceptable to society, and/or
2. affect the functioning of that individual's mind or body, either because of, or regardless of society, and/or
3. cause pain, fatigue, affect communication and/or reduce consciousness.

Disabled people are those people with *impairments* who are disabled by society.

To pay attention to the words we use is not to be "politically correct" but to struggle for a language which describes the denial of our human rights, locates our experience of inequality as a civil rights issue and, at the same time, creates a space to articulate our experience of our bodies. Separating out

“impairment” (ie the functional limitations of our bodies and minds) from “disability” (ie the disabling barriers of unequal access and negative attitudes) is the cornerstone of what is known as the social model of disability. This has enabled us, as disabled people, to challenge the assumption that impairment is an inevitable tragedy which can only be alleviated by cure or death and instead to assert that:

- the quality of our lives, and our life chances, are not inevitably determined by what our bodies can't do, or look like, or how our minds function. Like the women's movement, we say - anatomy is not destiny
- we therefore need to separate out “impairment” - the characteristics of our bodies and minds - from the way other people and society generally react to impairment
- prejudice, discrimination, services which disempower and segregate us; a failure to use resources to create accessible environments, technology to aid communication, provide personal assistance to aid daily living and so on - these are the disabling barriers that we experience
- people with physical, sensory, cognitive impairments, people with mental health difficulties are therefore disabled by the society in which we live
- and we use the term “disabled people” to describe what is done to us. This language politicises our experiences and it takes the focus away from our impairments being the problem and puts the responsibility onto the society in which we live.

This is why we don't use the term disability to mean impairment. Instead we use it to refer to prejudice and discrimination, just as racism and sexism refer to the prejudice and discrimination experienced by Black people and by women. A disabled person might say, therefore, "My impairment is the fact that I can't walk; my disability is the fact that the bus company only purchases inaccessible buses." Or, "My impairment is the fact that I can't speak; my disability is the fact that you won't take the time and trouble to learn how to communicate with me."

To use the term "people with disabilities" is to define us by our impairments because here the word "disability" means impairment - what our bodies can't do. It robs us of the language we need to describe oppression and discrimination. In contrast, to use disability to mean disabling barriers enables us to move away from the assumption that it is impairment which determines our life chances. If impairment determines our experiences then the only things that can be offered are treatments and cures, and services (residential care, segregated schooling etc) which prevent us from doing the kinds of things that non-disabled people do because we are not recognised as full human beings. It is this approach which leads to segregation and exclusion - and ultimately to the assumption that our lives are not worth living and that we would be better off dead, or not being born in the first place.

Like women, disabled people's politicisation has its roots in the assertion that "the personal is political", that our personal experiences of being denied opportunities are not to be explained by our bodily limitations (our impairments) but by the disabling social, environmental and attitudinal barriers which are a daily part of our lives. The social model of disability has given us the language to describe our experiences of discrimination and prejudice and has been as liberating for disabled people as feminism has been for women.

This is clearly illustrated by Liz Crow, when she wrote:

Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me with an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it.

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 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.

(1996, 206-7)

While the British disabled people's movement adopted the social model of disability about 15 years ago, it has taken us a long time to consistently use the word "disability" to mean oppression and to reclaim the word "impairment" as a value-free word to describe characteristics of our bodies. This development is reflected in my own writings: in *Pride against Prejudice*, published in 1991, I used the term disability to mean both oppression and impairment; by the time I edited *Encounters with Strangers*, five years later, I used it solely to mean oppression.

The development of the social model of disability has not just had a liberating effect on individual disabled people but has also had significant consequences for the kind of research which is carried out about our experiences. The whole focus on research is shifted when the issue under examination is not impairment but disabling barriers. This is illustrated by criticism of the questions asked in a survey of disabled people carried out by the British government in the late 1980s. The survey 's questions asked about personal experience of impairment, while Professor Mike Oliver – a disabled person himself – reconstructed the questions to focus on disabling barriers (Michael Oliver 1992, 104). For example;

What complaint causes your difficulty in holding, gripping or turning things?

became

What defects in the design of everyday equipment like bottles, jars and tins causes you difficulty in holding, gripping or turning them?

Have you attended a special school because of long-term health problems?

became

Have you attended a special school because of your education authority's policy of sending people with your impairment to such places?

Does your health problem/disability make it difficult for you to travel by bus?

became

Do poorly designed buses make it difficult for someone with your impairment to use them?

And a final example,

Can you tell me what is wrong with you? became

Can you tell me what is wrong with the organisation of your community resulting in your exclusion?

Over the last twenty years or so, disabled people have insisted that we are the experts on our experiences – rather than, for example, the government statisticians who wrote the questions above - and have challenged the way we are represented and our needs determined by others. In doing this, we have

followed the women's movement in asserting the power of personal experience.

THE VALIDITY OF PERSONAL EXPERIENCE OF OPPRESSION

All liberation movements have had to wrest the representation of their reality from those who oppress them. Disabled people are no different. Negative messages about impairment and disability are so taken for granted that they often pass unnoticed. Lois Keith has shown, for example, how impairment has a central position in the classics of girls' fiction and how this has been unnoticed and uncommented upon – until read by someone for whom impairment has personal meaning. Her analysis shows how girls were (are) learning, through books such as *Jane Eyre*, *Little Women*, *What Katy Did*, *Heidi*, that

(1) there is nothing good about being disabled; (2) disabled people have to learn the same qualities of submissive behaviour that women have always had to learn: patience, cheerfulness, and making the best of things; (3) impairment can be a punishment for bad behaviour, for evil thoughts or for not being a good enough person; (4) although disabled people should be pitied rather than punished, they can never be accepted; and(5) the impairment is curable. If you want to enough, if you love yourself enough (but not more than you love others), if you believe in God enough, you will be cured (2000, 7).

Commenting on the way that feminist writers see the world through “gendered eyes”, Keith asserts that, as a disabled woman, “I too look at the world differently and there are issues and ideas, apparently invisible to others, which are very real to me.” (2000, 9) I am not saying that all disabled women see the world in the same way, any more than all women – or even all feminists - see the world in the same way. What I am arguing for is a recognition of the value of subjectivity, and specifically the value of bringing personal experience of oppression to bear on analysis and interpretation of the world.

As perhaps the youngest civil rights movement, we are able to learn from the analyses of those who went before us. The way in which personal experience of oppression influences perception is powerfully illustrated by Chinua Achebe’s account of his and his fellow Nigerian students’ reaction to a novel by the Anglo-Irishman Joyce Carey, described when it was published in the 1950s as “the best novel ever written about Africa.” Far from identifying with the Nigerian “hero” of *Mister Johnson*, the young Nigerians saw him as an embarrassing and offensive representation of Black people: as Achebe writes “It began to dawn on me that although fiction was undoubtedly fictitious it could also be true or false, not with the truth or falsehood of a news item but as to its disinterestedness, its intention, its integrity” (2000, 33-34). Stereotypes, says Achebe, which arise from the oppression of the slave trade “poison the well-springs of our common humanity” (2000, 35).

The civil rights movement of disabled people has learnt – as have other civil rights movements - that all forms of prejudice have at their heart a refusal to acknowledge the common humanity shared by the oppressor and the oppressed. While one social group has the power to represent, through whatever media, the reality of those perceived as different there is always a danger that the “other” will be seen as not quite human. As long as non-disabled people retain the power to represent our reality, impairment will always mean at best a cause for treatment and cure, at worst a life not worth living. As Achebe says, “There is such a thing as absolute power over narrative. Those who secure this privilege for themselves can arrange stories about others pretty much where, and as, they like” (2000, 24).

Non-disabled people have had, and largely continue to have, “absolute power” over narrative when it comes to the representation of impairment in literature, film, television, art. In my own field of social policy research, non-disabled people continue to set the research agendas and analysis of our reality (although things are changing and we have some good allies). The consequences of this are seen, for example, in the feminist research on “carers”, that is research about situations where people have to rely on their families for help with daily living tasks. This research divided women into “carers and their dependents” and made invisible the experiences of women who need such support. Disabled and older women were identified as “other” and not included in the feminist analysis of women’s experiences. Instead,

they identified an “equal opportunities” issue for non-disabled women whose economic position suffers because of the unpaid caring work they carry out within the family. Some non-disabled feminists suggested that disabled and older women should therefore be consigned to residential care (for example, Gillian Dalley 1988; Janet Finch 1990; see Jenny Morris 1991, Chapter 6, and 1993, Chapter 3, for a full discussion).

Feminist analysis in this field thus resulted in disabled and older women being excluded from the category of “women” and classed as “dependents” whose existence was a threat to non-disabled women’s economic opportunities. Having silenced the voices of disabled and older women in the academic and media debates of the 1980s and early 1990s about “carers and their dependents”, this has continued in recent years with the identification of the children of disabled parents as “young carers” (see Lois Keith and Jenny Morris 1996 for a full discussion of this issue). This debate has particularly undermined disabled mothers as most of the situations where children are so identified are where women are parenting on their own.

Children of disabled parents have been described as “little angels” who are forced to “neglect their schoolwork and friends” in order to look after us. However, if we apply the social model of disability to the situation of disabled mothers we can see that there are a number of social factors which create the situation where children might have to provide some help to their parents.

Poverty is probably the most important social factor: impairment and illness often bring reduced earning power as well as higher daily living costs. Moreover, most of the research which identified households where children were providing some assistance to their parent were single parent households. The association of poverty with single parenthood therefore must also be a factor. Impairment and illness bring additional costs yet an increased risk of poverty also means that the resources are often not available to buy equipment or personal assistance. Disabled parents are often therefore forced to rely on others within their family for the help they need to go about their daily lives.

Another important barrier faced by disabled mothers is discriminatory professional attitudes. A few years ago the Maternity Alliance in Britain ran a conference for disabled parents and they shared their experiences of assumptions that they could not be fit parents. The attitudes of health and social services professionals can actually deter disabled parents from asking for practical assistance because there is a fear that their children will be taken away.

Even when services are available they are often delivered in ways which are inappropriate and disempowering. Services can create a need for a child to help by restricting the amount and the type of assistance that will be provided.

Disabling environments and inaccessible housing can also create a need for help.

A failure to understand the social model of disability lies at the heart of the dominant reaction to the situation where children are having to provide support to their disabled parent. This is illustrated by the following contrasting statements.

Disabling attitude

People who need help with the physical tasks of daily living are dependent.

If your child helps you put your shoes on, this involves a reversal of roles - you have become the child, and your child becomes your parent.

We need to recognise the role of “young carers” so that we can support these children in their “caring responsibilities, experiences and needs”.

Disability rights perspective

Independence is not about doing everything for yourself but about having control over how help is provided.

The need for help with daily living tasks does not undermine your ability to love and care for your child.

Disabled parents should not have to rely on our children for help as we have statutory rights to “practical assistance in the home” and to the adaptations and equipment we require.

We need to replace all the debates about “young carers” with a clear understanding about what rights disabled people have to receive practical assistance in their home. Current British legislation does give us this

entitlement. In many of the situations described in research and media stories about children of disabled parents, the parents had clear rights to practical assistance. Yet they were not getting these entitlements and unfortunately researchers and commentators have failed to highlight this. Instead the children of disabled parents have been given awards for being “children of courage” and the only practical help offered is the setting up of “young carers” projects which seek to support children and young people in their “caring” tasks, rather than ensure that their parents’ get the assistance they need.

We also need to link the issue to the wider campaign for human and civil rights. One local group in Britain is currently working to support 17 disabled mothers whose children have either been removed from them or who have been threatened with this. In 1999, the Spinal Injuries Association fought, successfully, to prevent the child of one disabled woman being removed from her at the point of birth. Most importantly, this needs to be identified as a feminist issue for it is to a considerable extent an issue for single parents - the majority of whom are women. The debate on “young carers” feeds into the attack on single parents - in each case there is an implicit if not an explicit attack on women’s ability to parent without the presence of a man in the household.

THE MEANING OF IMPAIRMENT

A social model approach to the difficulties faced by disabled parents means that we focus on the disabling barriers of unequal access and negative attitudes, rather than on impairment. However, the clear separation of the terms disability and impairment also enables us, or should enable us, to talk about impairment and its effect on our lives. As yet, however, it has been difficult and has felt dangerous to do this. It is difficult because it is not always obvious what restrictions are caused by impairment and what by disability, and dangerous because, to articulate any negative feelings about our experience of our bodies, may be to play into the hands of those who feel that our lives are not worth living. We share a lot with other civil rights movements but our form of oppression has a unique characteristic: it is not inherently distressing to be Black or a woman or gay whilst it may be to experience an impairment. We can, and do, assert the value of the life of someone with an impairment and struggle against the disabling barriers of unequal access and negative attitudes. We can also seek to change the perception of what is considered to be beautiful about human bodies and to celebrate the way ours are different. But to deny the distressing nature of the body's experience of, for example, arthritis or epilepsy, would be foolish.

This makes it even more important for us to challenge the way non-disabled people, including non-disabled feminists, assume a right to define and represent the experience and meaning of impairment. If we clearly separate

out disability and impairment, then we can campaign against the disabling barriers and attitudes which so influence our lives and the opportunities which we have. This does not justify, however, ignoring the experience of our bodies, even though the pressures to do this are considerable because of the way that our bodies have been considered as abnormal, as pitiful, as the cause of our lives not being worth living. Sensory impairment, physical impairment, intellectual impairments are seen as things to be avoided at all costs. In the face of this prejudice it is very important to assert that anatomy is not destiny and that it is instead the disabling barriers “out there” which determine the quality of our lives.

However, in doing this we have sometimes colluded with the idea that the “typical” disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment. In fact, the largest group of disabled people are those with learning difficulties (that is, cognitive impairments), and most disabled people with a *physical* impairment are women, are over the age of 60, have a chronic or progressive condition such as arthritis or multiple sclerosis, feel unwell a lot of the time and if they use a wheelchair they only do so occasionally. Yet when I have tried to raise the importance of addressing the actual experiences of our bodies, I have been accused of “not dealing with the real world” and of feeding into non-disabled people’s pity of us. Indeed, I worry myself that if we *do* start talking about the negative aspects of living with impairment and illness, non-disabled people will

turn round and say, “there you are then, we always knew that your lives weren’t worth living.”

This means, however, that we are forced into situations of denying the experience of our bodies, of trying to conform to the outside world’s view of what it is to be a full human being. This kind of pressure is represented in a piece of writing by Michele Wates (1994, 91-2). This describes the way one disabled woman feels that, when out in public, she must counter the negative way that people react to what she looks like and how her body behaves - in this particular case a man coming towards her down the street.

Seeing the averted gaze of pity, she found herself preparing for the moment when they would pass one another on the narrow path. She could not help herself from wanting people, even complete strangers like this man, to notice that although she might be dragging herself along like a wounded animal, her eyes were bright, she had a ready smile and her voice, if he should have reason to hear it, was up and out; confident.

It was an American older woman who wrote: “If I feel shame in my lack of strength, I will have let someone else in my head for the rest of my life” (Barbara Macdonald with Cynthia Rich 1983, 32).

Living in a sexist and a heterosexist society as we do, all of us, non-

disabled and disabled women, find that our behaviour and appearance are policed by men. Sexist and heterosexist values tell us what kind of appearance we should aim for, what kind of behaviour is acceptable. Society's reaction to impairment, to bodies which are very different from the norm, means that disabled women are either attractive in spite of their impairment or unattractive because of their impairment. There is little or no room for celebrating our different bodies, and neither is there room for recognising the negative aspects of impairment without undermining the value of our lives.

As Liz Crow writes, we need to put back the experience of impairment into our politics (1996). We need to write about, research and analyse the personal experience of our bodies and our minds for if we don't impose our own definitions and perspectives then the non-disabled world will continue to do it for us in ways which alienate and disempower us. Some people have reacted to this position by saying that there is nothing political to be said about impairment - impairment belongs to the personal world where everyone is different and there are such variations in individual experiences that there are few generalisations to be made. The problem is that if we don't express the experience of our bodies, others will do it for us. If we don't confront what we need as a result of illness, pain, chronic conditions which inhibit our lives, then health services and support services will continue to be run in ways which disempower us. If we don't engage in the debates about old age then as we age we will find that the battles we thought we had won as younger disabled

people are of no use to us whatsoever. Most importantly, if we don't take over the representation of the negative aspects of impairment then its meaning to others will continue to undermine us.

Adrienne Rich said it all in her poem:

The problem, unstated till now, is how
to live in a damaged body
in a world where pain is meant to be gagged
uncured, un-grieved-over. The problem is
to connect, without hysteria, the pain
of anyone's body with the pain of the body's world.

(Adrienne Rich 1993)

We need to somehow get to the space where the courage of living with impairment is acknowledged without being accompanied by the unspoken "I would rather be dead"; where sympathy does not mean pity; where an expression of regret for what is lost through impairment does not mean that our lives are not worth living.

We are a long way from this way of perceiving impairment.

DIFFERENCE

The meaning that impairment has for non-disabled people is a real barrier to our own recognition of our difference. As Nancy Mairs says, “To know that one arouses dismay and fear and pity simply sickens the spirit of anyone, whether sound of limb and mind or not” (1996,103). The way others recognise our difference can therefore mean that our response is to deny our difference. But we *are* different and many artists have started to celebrate our different bodies. We are also different in another sense. We have the same human and civil rights as other human beings and other citizens but it is not only prejudice and discrimination which have denied us these rights. Human and civil rights are about equal access, about what we all share in common - either by virtue of our common humanity or our common citizenship of a particular country. However, in many situations, the human and civil rights of disabled people cannot be promoted without particular action being taken, resources being made available, which would give us equal access. Specific entitlements (ie “different treatment”) are necessary for equal access. To take two examples:

- disabled children will not have equal access to education unless they have an entitlement to changes in the physical environment of schools to ensure physical access, the provision of equipment, materials, interpreters, support to make the curriculum accessible, and the implementation of anti-bullying policies.
- disabled people will not be able to access their human right to a family

life unless they have an entitlement to accessible housing, equipment and personal assistance.

Up until now, the recognition of our difference has been the gateway to a *denial* of human and civil rights: to be recognised as “severely disabled”, for example, all too often leads to segregation in an institutional setting. We need to change this so that the recognition of our difference becomes the gateway to the provision of what we require in order to access our human and civil rights. We have to recognise that disabled people will not get access to full human and civil rights by being treated the same as non-disabled people. We experience disabling barriers - unequal access to education, inaccessible housing to name just two - which non-disabled people do not face. We experience higher costs of daily living - created by a need for personal assistance, sign language interpreters, supporters, mobility equipment, communication equipment - which non-disabled people do not face. We make higher demands on health services and our access to health services is restricted by assumptions that the quality of our lives does not warrant such expenditure.

Unless we have entitlements to action and resources to tackle these disabling barriers then we cannot achieve equality. It is also important to understand that all of this is tied up with our right to exist. Generally, non-disabled people are undecided about whether they want a society which

contains people who look different, who need support, who need changes to make buildings and houses more accessible to them, who need more resources for education and health, etc. In a lot of situations they would rather we weren't born, or were "allowed to die."

However, if non-disabled people do accept our right to exist then they should also accept our common humanity and therefore our right to equality - as citizens and as human beings. We can't get equality or a good quality of life unless we are given entitlements to different treatment - to changes and resources which enable us to get equal access - to jobs, to housing, to leisure and political activities, and so on. As someone at a Conference on Citizenship, Self Determination and Political Action, held in 1998 in Sydney, Australia said, "Why is it OK to say we can be denied our rights as citizens because it costs too much?" Or as Nancy Mairs writes in response to the fiscal conservatives squeal "Why should I pay for someone else's misfortune?" – "Because that's what human beings do: take care of one another" (1996,122). Of course there are plenty of times in our world's history, and plenty of places in the world today, where human beings have not and do not take care of one another – and where human and civil rights have been denied as a result. The point is that, in the twenty-first century, we should have reached a place where resources are used to promote the human and civil rights of all the groups who make up our very diverse societies. Mairs' statement does however raise the question of what we might mean by "taking care" and whether it is possible to

both be “dependent” on others and to have one’s human and civil rights fully recognised.

“CARE” AND “DEPENDENCY”

As Tom Shakespeare has identified, there have been two alternative models put forward for re-conceptualising “care” (2000, 72). The first is articulated by the disabled people’s movement. This redefines independence as having choice and control over the assistance required rather than doing everything for yourself; and asserts that disabled people do not want or need “care” but instead want their rights as citizens recognised. The second model is the feminist ethics of care which is based on a recognition of interdependence, relationships and responsibilities, and criticises notions of autonomy, independence and individual rights as being too much based on a masculine view of people as separate from each other.

I want to highlight the importance of impairment for this debate and to argue that we need an ethics of care which recognises our common humanity and the consequences for all of us of a denial of human rights.

Even if dependency is recognised as an essential part of the human condition – as Selma Sevenhuijsen (1998), amongst others, asserts – this should not obscure the fact that some people’s experience of their bodies (their impairment) places them at much greater risk of losing their human (and civil) rights than the majority of the population. Someone, for example, who does not

use speech to communicate, has a high level of cognitive impairment, and/or relies on others for help with all their bodily functions is very vulnerable to being denied a good quality of life. While it may help to recognise the way we are all – as social beings – dependent on one another, I would argue that it is not actually the case that “disabled people’s limitations are not qualitatively different from those of other human beings” (Shakespeare 2000, 77).

When someone depends on someone else to do physical things for them, the more personal the task the greater the potential for abuse of human rights – and the greater the potential for the “caregiver” to protect and promote human rights. To depend on others for assistance in intimate tasks is not the same as depending on a mechanic to service your car. In each situation, we want the assistance to be reliable, competent and we want to be treated with respect, but there are qualitative differences in the experience which are rooted in the experience of impairment. Julia Twigg’s recent qualitative research on older people’s experiences of being bathed highlights this quite clearly: “One person, strong and able, stands above and over another who is frail and physically vulnerable, forced to rely on their strength and goodwill. Being naked in the face of someone who is not, contains a powerful dynamic of domination and vulnerability, and it is often used in situations of interrogation and torture as a means of subjugating the individual” (2000, 21).

We need to challenge the social construction of dependency but we should not at the same time deny the experience of our bodies and the

consequences for the provision of assistance. Vulnerability is created by one person having a greater need for physical assistance than the person who is in a position to provide it, *and* by the nature of the assistance required. This is why a focus on human rights is so important in our challenge to the meaning of care.

Communication and cognitive impairments – like physical impairments - also create a particular type of dependency on others. This was starkly brought home to me in my recent research concerning young disabled people who have high levels of support needs. I visited one young man at the residential school he had been attending since the age of four. According to his parents, care staff and teachers he had no way of indicating “yes” or “no”, no way of communicating his preferences or choices. When I observed him in classrooms and where he lived, he had no discernible interaction with others, indeed he spent a large part of each day asleep. During the course of the research project he left school and went back to live with his parents. I visited him at the day centre he now attends. There I observed him actively participating in relationships with the care staff and other disabled young people. He “said” yes by looking straight at you, and looked away for no. His smile was so broad it took up all of his face and he never slept during the day – he was too interested and involved in what was going on. This transformation had been brought about by a “care” relationship which started with his human right to communicate and which sought ways to make this possible. His impairment meant that this young man *depended* entirely on others to

recognise and facilitate his access to this most fundamental of human rights.

Those working with people who have dementia have also identified the potential for the caring relationship to promote or abuse human rights, and indeed how the way care is delivered can also affect the experience of impairment. Thus, “‘Bad’ care fails to take personhood seriously, and allows the individual to fall apart, a prey to the dire combination of cognitive impairment and emotional distress. ‘Good’ care honours personhood and provides increasing interpersonal compensation and reassurance as individual powers fail” (Tom Kitwood and Kathleen Bredin 1992, 44).

Whether we talk in terms of “independent living” or “community care”, It is important to separate out means and ends. Social policy debates often focus on the means without paying enough attention to the ends. So we argue about cash payments versus services, mainstream versus special schools, formal (ie paid helpers) versus informal (ie unpaid, based on relationships of blood and/or affection) care. The real point is whether these means deliver the ends – which is the protection and promotion of human rights.

It is of course not an entirely simple question what we mean by human rights but the key point is that they are universal, they are what we have because of our commonality, what we share with all human beings throughout the world. The human rights which are written down in the Universal Declaration of Human Rights (United Nations 1948) were articulated in order to

prevent a situation ever again occurring where a State designated groups of people as sub-human and aimed to obliterate them. When disabled people in Britain first started to come together to challenge the prejudice they experienced, they drew on this human rights perspective for their starting point:

All human beings have an equal right to live, to eat adequately, to housing, to clean water, to a basic standard of health and hygiene, to privacy, to education, to work, to marry (or not), have children (or not), to determine their own sexuality, to state an opinion, to participate in decisions which affect their lives, to share fully in the social life of their community and to contribute to the well being of others to the full extent of their capabilities (*In from the Cold*, June 1981, pp 19-20).

Whatever “care” is - whether it is in the form of formal services, cash payments, or personal relationships – if it does not enable someone “to state an opinion”, “to fully participate in decisions which affect their lives”, and “to share fully in the social life of their community”, then it will be unethical. We need an ethics of care which is based on the principle that to deny the human rights of our fellow human beings is to undermine our own humanity. We need an ethics of care which recognises that anyone – whatever their level of communication or cognitive impairment – can express preferences. We need an ethics of care which aims to enable people to participate in decisions which affect them, and to be involved in the life of their community. Most importantly,

we need an ethics of care which, while starting from the position that everyone has the same human rights, yet recognises the additional requirements that some people have in order to access those human rights. The recognition of our difference (including our dependence), because of our impairments, can thus become a passport to the recognition of our common humanity.

Acknowledgements

I owe a great debt to Susan Hemmings, and to the ideas she has developed about rights and the social model of disability. I am also grateful to her and to Lois Keith for discussing an earlier draft of this paper with me.

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