

# The Meaning of Independent Living in the 3<sup>rd</sup> Millenium

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I've used the opportunity of preparing a paper for this lecture to reflect on where we at in terms of 'independent living' at the end of this millenium and what barriers and opportunities we face as we go into the next millenium.

The concept of, and demand for, independent living grew out of the experiences of people who were incarcerated in residential homes. One of the features of the post-second world war period in Britain was the development of charities, often named after the individuals that founded them. These charities were motivated by a very real concern that society and government were not making proper provision for disabled people. They thus became service providers themselves, and because the prevailing attitude was that people who have physical or sensory impairments, or learning difficulties need looking after, the most common service provided was residential care.

One of the things we have to beware of in the development of the Independent Living Movement is the tendency for progressive ideas to be watered down, at worst completely distorted, when put into practice. It is worth bearing in mind the humanitarian intentions of Leonard Cheshire, the founder of what is now the

largest organisation providing institutional care for disabled people. The Leonard Cheshire Foundation's Mission Statement commits itself to 'unquestioning recognition of [ disabled people's] full human rights'. Yet that is not the experience of many people who use its services. The Independent Living Movement faces a similar danger of its radical ideas being turned in practice into something different from the original intentions.

It was in the 1970s that a group of people in one Leonard Cheshire Home, Le Court in Hampshire, came to a key understanding about their experiences: namely an understanding that, just because they needed help with going to bed, this did not mean that they had to be put in their pyjamas at 6 o'clock in the evening. This is what the social model of disability is about: that it is not impairment in itself which restricts what someone can do, but the lack of suitable assistance; it is not impairment in itself which separates someone from society but the attitude that segregation is an appropriate response to their needs. People living at Le Court started to object to the way that society was spending large sums of money to keep them in a situation where they could not choose when they got up, when they went to bed, whether they went out to the local pub, whether they had sexual relationships, and so on. Such a situation separated them from society, denied them opportunities for employment, a home of their own, a family – in other words denied their human rights.

With assistance from the Leonard Cheshire Foundation, three individuals – John Evans, Liz Briggs and Peter Wade – pioneered the development of independent living by persuading their social

services departments to fund the personal assistance they needed in their homes, rather than through purchasing a place for them in residential care (Hampshire Centre for Independent Living, 1986). At the same time, in other parts of the country, other people such as Maggie Hines and Ken Davis in Derbyshire, were successful in persuading social housing providers and social services authorities to make it possible for them to move out of residential care.

However, moving out of residential care did not guarantee control over your life. As long as people remained dependent on services over which they had no control they still could not choose when they got up and when they went to bed, and so on. So the growing disabled people's movement and the increasing number of Centres for Independent Living put pressure on local authorities to provide more empowering services and, in particular, to give disabled people the cash so that they could purchase the help they needed themselves. By 1990, although the 1948 National Assistance Act prohibited local authorities from making cash payments in lieu of services, almost one in four social services departments were actually making direct payments to disabled people so that they could employ their own helpers and a number of others were making 'indirect payments' through voluntary organisations (Morris, 1993, p.26).

The whole idea of disabled people being enabled to purchase their own assistance was boosted by the establishment in 1988 of the Independent Living Fund, a government funded charity set up with an initial budget of £5million to make cash payments to people so that they could pay for their own personal assistance. This was

offered in response to disability organisations' opposition to changes in the benefit system in the late 1980s which abolished the domestic needs allowance. Although there had been a very low take up of the domestic needs allowance (for various reasons including poor advertising) there was a huge take up of ILF grants and within four years its annual budget had reached £97million and over 18,000 people were receiving ILF awards.

In the meantime, the disability movement's campaign for the government to legalise direct payments received increasing support and finally resulted in the Community Care (Direct Payments) Act 1996. It has to be said that, while this was undoubtedly a victory for the Independent Living Movement it has also been part of increasing attempts by central and local government to control the amount of money which people can get to pay for personal assistance in their own homes. While the original ILF grants were based on actual expenditure, limits were soon put on the total that could be claimed; means-testing (through so-called charging policies) is rapidly being applied to local authority services and direct payments; and many local authorities are now imposing a 'cap' on the amount that can be spent on supporting people to live in their own homes – with the implication that if it costs over this amount they will have to enter residential care (Campbell, 1999).

At the same time, the broader disability movement has made real progress on the issue of civil rights – which of course underpins the whole concept of independent living. There's not much point in having control over the help you need if you can't use public

transport, get a job, get the education you need, get access to goods and services on the same terms as everyone else. When the first civil rights bills were introduced into Parliament as private members' bills during the early 1980s, the common reaction was that anti-discrimination legislation wasn't needed for disabled people because we didn't experience discrimination – everyone wanted to be nice to disabled people because they felt sorry for us and if we couldn't get employment it was because we were unable to do a job, not because of prejudicial attitudes.

We moved a long way over the course of 20 years or so towards a more general acceptance that there is discrimination and that employers and service providers should make adjustments to accommodate us. The Disability Discrimination Act reflects a victory in that it does attempt to address discriminatory attitudes and disabling barriers but it remains only a partial victory for reasons which have been well articulated by BCODP, not least because it remains based on a medical model of disability and excludes crucial areas of discrimination – transport and education.

So, as we go into the next millenium we face a situation where, although we have achieved a lot in the last 20 years, there is yet more to be done. What I want to do is to explore some of the more fundamental barriers we face in furthering the principles of independent living, of disabled people having choice and control in their lives.

### **The denial of a language to describe our oppression**

The government recently commissioned Demos, a think tank, to do some work on 'ways in which genuine progress can be made in the coming decade to overcome the many barriers that affect the rights and quality of life of people facing disability'. Demos wrote a briefing paper as the basis for a 'symposium' held in London in April this year. While the paper's title was 'An inclusive future? Disability, social change and potential opportunities for greater inclusion by 2010' its authors failed to take on board the starting point for our movement's analysis of our social exclusion – namely the difference between disability and impairment. According to Demos, 'disability as a concept covers a wide spectrum of medical impairments'.

The disabled people's movement does not use the word disability to mean impairment. Our political theory is based on the separating out of impairments – the functional limitations of someone's body or mind – from disabling barriers: the prejudicial attitudes and unequal access which result in our social exclusion. We are disabled by what society does to us: therefore disability, like racism or sexism, is the word we use to describe our oppression. One of the most excluding things you can do to a group of people is to refuse to acknowledge the language they use to describe their experiences of inequality.

Unfortunately, it is very common for policy-makers and professionals these days to say that they understand the social model of disability, and yet continue to use the language of the medical model. This is not mere detail, it is a fundamental

undermining of our struggle for equal access to a decent quality of life, as I shall show.

### **The need for full civil rights legislation**

The importance of getting the language, and thus the analysis of inequality, right is illustrated by the inadequacies of the Disability Discrimination Act which, in its current form, can only promote independent living and civil rights for disabled people in a very limited way.

The DDA uses a medical model of disability in that it says ‘a person has a *disability*...if he has a physical or mental *impairment* which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.’ Anti-discrimination legislation should focus on discrimination, not on the characteristics of the person being discriminated against. The current DDA is similar to having an anti-discrimination law covering race focussing on how dark someone’s skin is, or how ‘foreign’ their accent, in determining whether they are protected against discrimination. Instead of being offered full protection against discrimination, the DDA asks ‘is your impairment significant enough to give you access to fair treatment?’

The problems with this medical model definition of *who* is covered by the Act are also related to the limitations of *what* is covered. The DDA does not cover disabling barriers created by social organisations. It cannot because, by definition, the focus of the legislation is on limitations caused by impairment, rather than limitations caused by social organisations (the disabling barriers).

It therefore does not provide protection from, for example, the institutional discrimination resulting from the way education is delivered, or public transport provided. Neither does it provide protection from unequal access or outright denial of health care. For example, the largest group of children who have heart disease in Britain are never, ever considered, or even assessed, for a heart transplant. This is because they have Down's Syndrome. When asked to defend this policy, the medical director at Harefield Hospital, which carries out more heart transplants than any other centre in the world, said 'It's not just Down's we are seemingly discriminated against. It is anybody with any disability. We take, when faced with a choice, the person who is the most *whole*, as it were'. (*The Guardian Weekend*, August 10 1996, p.18).

A failure to understand the importance of separating out disabling barriers and impairment is also key to the next barrier we face in our struggle for independent living.

### **A lack of understanding of the relationship between human rights, civil rights and entitlements**

Disabled people insist that we are human beings and that we should therefore be accorded our human rights; we also insist that we are citizens, like everyone else, and that we should have access to everything that all other citizens of this country have access to. But in order to access our human and civil rights, in order to be able to do the *same* things as nondisabled people, 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. When the pioneers of the Independent Living Movement were asserting their human rights to freedom of movement, to form relationships, their civil rights to equal access to employment, to housing and so on, they were clear that in order to access these human and civil rights they needed specific action and assistance. In other words, in order to be the same as everyone else, we need our difference and our specific needs to be recognised.

We need human rights and civil rights but we also need specific entitlements. Three statements illustrate the differences between these and the relationship between them:

'Disabled people have the right to have children.' This is an assertion of a human right - it is about our common humanity, what we share universally with all human beings, although of course many disabled people don't have access to this human right.

Disabled parents have the right to sit with their children in the cinema.' This is an assertion of a civil right - again it is about what we share in common with others, but in this case as citizens of this country: we should have access to the things that nondisabled people have access to on the same terms as them. We need our civil rights in order to access our human rights. This particular right should be protected under the DDA but we will continue to have difficulty accessing it when new cinemas continue to be built - like the new IMAX in London. - which segregate wheelchair users from other members of the public.

'Disabled parents have the right to assistance with looking after their children in their own homes if they need it.' In order to look after their children disabled parents may need additional assistance, adaptations or equipment. If we don't have an entitlement to these things then we will not be able to access our human and civil rights to be parents. Ultimately, the promotion of our human and civil rights therefore is based, not only on a recognition of what we have in common with all human beings and all citizens, but also on a recognition of our difference and what we need to happen in order that we have access to the same rights as everyone else. Disabled parents do in fact have an entitlement under the Chronically Sick and Disabled Persons Act 1970 to 'practical assistance in the home' although it is notoriously difficult to get access to this entitlement.

What the pioneers of the Independent Living Movement were struggling against, and what we continue to struggle against, is the reality that when our difference is recognised, it is recognised in ways which segregate us, which demean us, which discriminate against us. Independent living can only be promoted – and thus our human and civil rights achieved – if the way difference is perceived is transformed. We don't want to deny our difference but to ensure that it is recognised in a way which acknowledges the additional things that we need in order to access our human and civil rights.

Incidentally, this is why the government's intended advertising campaign which uses the slogan 'see the person not the disability' is so wrong. This is not only an attempt to deny the feelings that

people have about difference, it is also to deny that we *are* different – it is a denial of the prejudice we experience, a denial the things that we need to happen in order that we can access our human and civil rights.

### **The meaning of dependency**

We have to confront what our difference means. We have to confront the fact that most nondisabled people, when faced with the prospect of significant impairment, would rather be dead. This is why one of the things that the Independent Living Movement has struggled against has been the meaning of dependency, and the meaning of independence, in Western culture. Dependency is associated with being helpless, powerless, vulnerable. It is also associated with being a child, a woman and being old.

Independence, in contrast, is associated with being in control, in charge, with capability. It is also associated with being a man and being young.

The Independent Living Movement has tried to break the relationship between having choice and control in your life, and being able to physically do things for yourself. Fear of physical dependency is a very real thing: in surveys of older people the most common reason given for support of voluntary euthanasia is not fear of pain but fear of having to rely on others for physical help. The Independent Living Movement has challenged the idea that to rely on others for physical help inevitably means a loss of choice and control, an experience of inequality, a loss of human dignity. This may have been how relying on others for help is traditionally experienced, but this is because of the social context,

because of the unequal power relationship between those giving the help and those receiving it.

One of the most illuminating experiences I had recently was of running a training course for disabled people who live in residential homes. These are people who in their daily lives have no sense of an entitlement to the assistance they need, who are forever being made to feel a burden and demanding, who have to wait to go to the toilet, have to fit in with the Home's routines for mealtimes, bedtimes and getting up times, who have to rely on the goodwill of others if they want to go to the cinema or down to the pub.

The two day training courses are residential and are run in four star hotels. During the course of two days in a hotel, the disabled people received a service from the hotel staff which was delivered in a spirit of their entitlement as customers. The training we were delivering was about empowerment but probably the most empowering thing for them was the experience of being asked by the hotel staff what they would like, being asked whether everything was satisfactory, of being treated with respect. The staff at the hotel, of course, may have had the same prejudices as anyone else about disabled people, but their 'customer care' training did not allow them to express this. Perhaps this same training should be provided to those working in residential homes and local authority home care services.

The Independent Living Movement aims to fundamentally change the experience of receiving assistance. Giving people the purchasing power is the most direct way of redressing an unequal

power relationship, the most effective way of turning someone from a 'dependent' into someone who decides who delivers the help they need, how and when.

Yet there are experiences of dependency which the Independent Living Movement has not yet really touched, and indeed there are growing numbers of people with these experiences (Morris, 1999a). Increasing numbers of children who have a combination of physical and sensory impairments and learning difficulties are surviving into adulthood. At the same time, there are increasing numbers of young people with significant brain injury as a result of surviving accidents which would previously have killed them. And of course there are increasing numbers of frail older people, particularly those with dementia. These are the new 'customers' of the private and voluntary organisations providing residential care. The most disabling barrier many of them face is the assumption that significant communication and/or cognitive impairment means that they cannot make their preferences known and they cannot make choices.

We have to extend our critique of the meaning of dependency to people in this situation. This will also mean developing new ways of ensuring that people have choice and control. CILs are currently exploring how direct payments can be used by people who do not want to employ their own personal assistants. For example the West of England Coalition of Disabled People are seeking funding for a Partnership Operated Personal Assistance Scheme, where the scheme will act as the employer but the disabled person will be involved in recruiting and will have

responsibility for managing the personal assistant on a day to day basis (Morris, 1999b, p.35). In the new millenium we will need to go further and seek ways of extending choice and control to people whose cognitive impairments require us to redefine involvement in deciding who gives you help, what kind of help and how it is delivered. We need to learn about different ways of understanding how people communicate their preferences and their experiences, for example from the pioneering work done by the consultancy Triangle who work with children with 'complex needs' (Triangle, 1999a, b), from the work that Phoebe Caldwell has done with people with significant learning difficulties (Caldwell, 1996,1998) , and from developments in services for people with dementia, such as dementia care mapping – which uses close observation to understand experience.

### **The social construction of 'carers'**

One of the key barriers that the Independent Living Movement has always faced has been the assumption that the main source of receiving personal assistance will in fact be within personal relationships, within the family. The social construction of dependency has also had significant consequences for how these relationships have been defined. Over the last 20 years or so, researchers, policymakers and social and health services professionals have defined family members and friends who provide help to older and disabled people as 'carers' and those they 'care for' as 'dependents'. The 1980s saw a plethora of studies of so-called 'informal carers' where the role of 'caring' was defined as a 'taking charge' of the person who needs practical assistance and the voices of the 'cared for' – and the rights of

disabled and older people to adequate support which would give them choice and control in their lives – were obscured.

Ironically, carers as a pressure group started off as a self-help, grass roots organisation, with a strong relationship with an organisation of disabled people, the Spinal Injuries Association, and with the aim of giving women the support and confidence to refuse to act as unpaid helpers. Its aims and purpose became subverted into a professional, national organisation, funded by government, whose aim is to establish informal caring as a career, with a carers' income, protection of pension and other benefits (Morris, 1993, pp.31-40). In so doing, campaigners, together with the researchers in this field, have colluded with the government's position that public resources will never be adequate to provide the support needed by older and disabled people and their insistence that, to quote a government white paper published in 1981, 'Care in the community must increasingly mean care *by* the community' (Department of Health, 1981, paragraph 1.9).

The 'carers' issue of the 1990s has been the identification of children of disabled parents as 'young carers' and the way this has happened illustrates the ideological battles disabled people face (Keith and Morris, 1996).

The research studies of, the campaigning on, and the media interest in 'young carers' have tended to repeat two things which were common to the earlier debate on carers generally. They have defined and named a role, 'young carers', which until the children and young people came into contact with researchers or

professionals, was not how they described themselves. And secondly, the main policy issue has been defined as providing services to 'young carers' which would ease the 'burden of caring', rather than providing assistance to parents which prevent them having to rely on their children.

One of the factors which most seems to fascinate researchers, policymakers and professionals is the notion that there is role reversal going on where the children of disabled parents take responsibility for their parent and the parent becomes the 'cared for' party in the relationship.

A juxtaposition of the fundamentally different ways of seeing this relationship illustrates the way that disabling attitudes get in the way of recognising disabled people's human and civil rights, and lead to a denial of the entitlement to additional assistance required.

### 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'.

We need research on how many 'young carers' there are.

### 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 research on whether disabled parents are able to access their entitlements, etc.

The disabling attitudes held by researchers and professionals lead to a failure to recognise the additional things that disabled people need to access their civil and human rights and to deliver these as entitlements. In contrast a disability equality perspective redefines the problem as a civil rights issue.

In the new millenium we will particularly need to address the undermining of our entitlements which followed the House of Lords ruling known as the 'Gloucestershire Judgement' – which enabled

local authorities to take levels of resources into account when assessing need for assistance. The previous and current government's resistance to redressing this situation is a reflection of their failure to recognise or address the Independent Living Movement's demand for a level playing field. This is also a factor in the current struggles over welfare reform and the funding of the community care system.

### **Means-testing and the erosion of the universalist principle**

The principle of universalism is about creating a level playing field and it is a particularly important principle for disabled people. At the moment, the social security system makes a small recompense to those who incur extra daily living costs because of mobility impairments or personal care needs – in the form of disability living allowance. These payments are not means-tested because they are to pay for costs over and above what other people – who do not have mobility impairments or personal assistance needs – incur.

Unfortunately, the principle of universalism is not strongly enough applied and is currently under attack anyway. This is one of the biggest struggles that we face in the new millennium, to get politicians to understand the concept of a level playing field and the relationship between entitlements and human and civil rights.

The Labour government has dug itself into a hole by promising not to raise taxes – and yet to increase expenditure on health and education. So far, it has actually managed to raise taxes by stealth in order to finance this expenditure but in the medium to

long term it knows that it has to cut the social security budget, particularly the numbers of people claiming incapacity benefit. It also has to keep a lid on the potential expansion of resources needed for enabling people to live in the community.

Means-testing is the solution to this dilemma: local authorities are forced more and more into means-testing services (which includes means-testing direct payments); ILF grants are means-tested; and, having abandoned fundamental reform of the social security system, the government is trying to force through means-testing of incapacity benefit and a reduction in the number of people who will receive it.

The charity ideas about disabled people are still very strong – if we conform to the stereotype of the poor disabled person who is forever dependent on others then we can expect some help from the state and the taxpayer. But we can only expect a safety net to prevent us falling through into utter destitution, we cannot expect a level playing field which would enable us to aim for the same quality of life as those who do not need assistance in their daily lives.

The whole debate about the future of the welfare state is dominated by a failure to understand what disabled people need in order to access human and civil rights . We experience disabling barriers which nondisabled 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 nondisabled people

do not face. Unless we have a welfare state which gives us an entitlement to resources to tackle these barriers and to provide this assistance then we cannot achieve our human and civil rights.

We particularly need to get the message through to the government that its policies of creating opportunities for disabled people in the labour market will not work unless the community care system stops means-testing the provision of services and direct payments. There are many people who currently use direct payments and ILF grants for whom paid employment is out of the question because it would just not be economically viable. There are others, currently in paid employment, who have benefitted from Independent Living Schemes set up by local authorities which do not currently means-test them. Yet the pressure to means-test is growing stronger and will be a key struggle for the Independent Living Movement over the next few years. We can only hope to win this argument if we can get central and local government to understand the concept of a level playing field.

### **Resources are put into professionals rather than disabled people**

The post-war development of the welfare state saw huge resources go into the training and employment of people who apply their 'expertise' to our lives. This went along with identifying our needs as 'special' which therefore have to be met in ways which separate, segregate us from the mainstream. One of the key things that the Independent Living Movement has done is to insist that our needs are not 'special' at all, we want the same

things as everyone else, it's just that we need particular kinds of assistance in order to achieve this.

Over the years, I have been to a number of meetings in the role of advocate or friend where someone is trying to get the help they need out of the health and social services system – and in the research I have done I have interviewed many people undergoing the same struggle. It never ceases to amaze me that the professionals and services with which people engage are often unable to provide the only things which would make a difference to their lives. My friend who was facing discharge from a psychiatric unit knew that she needed someone with empathy to be with her – not all the time but at crucial times when she was vulnerable to emotional distress. A friend who had just given birth knew that she needed someone to come into her home to help her with the tasks she needed help with at the times she needed the help. Yet, in both situations, we sat in a room with people – whose combined salaries cost the taxpayer more than £150,000 per year - to hear them tell us that this kind of help was precisely what was not available, while the help which was available was disempowering, dehumanising and often more expensive.

What disabled people want are advocates, training in self-advocacy, access to mentors and peer support. We want help with sorting out what it is that would make a difference to our lives and access to support which is delivered in a way which enables us to be included in society. The Personal Assistance Support Schemes developed by CILs are a model for providing self-advocacy, advocacy and peer support. In the new millenium we

need resources to go into these kinds of services rather than into local authority social work and care management.

### **The role of charities**

Another factor which threatens to get in the way of the promotion of independent living is the role of charities like the Leonard Cheshire Foundation, MENCAP, Scope, etc. In the past, these organisations have been both service providers and have sought to speak on behalf of disabled people, using their position as service providers. The disability movement has significantly undermined their credibility as a voice of disabled people and organisations such as Scope and MENCAP are gradually involving more and more disabled people in the running of their organisations.

However, many of these organisations still have large amounts of capital tied up in buildings. This particular use of capital inevitably means that it is used to separate disabled people from their communities because it is about taking them into buildings, whether they are residential homes or day centres, which are solely for disabled people. This generates jobs in segregated settings, creating a need to raise revenue to pay people's salaries, thus the need for fundraising and contracts with local authority purchasers. The jobs of those throughout the organisation are thus dependent on continuing to segregate disabled people from the rest of society.

Some of these organisations have of course seen the writing on the wall and are entering into contracts with local authorities to

provide so-called independent living schemes and to develop services such as the Leonard Cheshire Foundation's Care at Home scheme.

Of course, there are people within these organisations who have a genuine commitment and understanding of independent living. But there are also those who use the rhetoric to sell themselves in the new contract culture. In this kind of situation, one of the most important things that the wider disability movement can do is to seize any opportunity available to make contact with people who live in residential care or who use services which institutionalise them within their own home. One example of this is the Empowerment Project run by Clare Evans. This resulted from a successful Lottery application from Leonard Cheshire Foundation to run empowerment courses for its service users. When they appointed Clare Evans as the co-ordinator they got a disabled woman with enormous experience of working to change organisations, of working in empowering ways to enable people who use services to determine how those services are run.

There was some criticism of her and those of us, like myself, who she employed as freelance trainers. But we need to seize opportunities like this to work with disabled people who are in the most oppressive situations. It has been the most difficult work I have ever done, because the level of disempowerment amongst the participants on the training courses has been so great. Yet it has also been the most rewarding because the potential for making a real difference to people's lives is enormous.

In the new millenium the Independent Living Movement needs to reach out to people who are in residential care, to people who, while they are living in their own homes, are yet institutionalised within them by services over which they have no control. One of our aims must be the demolition of all those buildings – many of them hidden away in the depths of the countryside – where disabled people are segregated from society. And we need to work with local authorities commissioning officers to ensure that the services they purchase on our behalf give us choice and control over our lives.

### **Independent living and human rights**

The European Convention on Human Rights, and now the Human Rights Act 1998 – which will be implemented in the year 2000, sets out everyone's right to be free from 'inhuman or degrading treatment'; the right to 'liberty'; to 'respect for private and family life'; to 'freedom of thought' and 'freedom of expression'. These are the standards against which any service should be measured.

In the work I've been doing recently, I have met people who are subject to 'inhuman and degrading treatment' - people whose so-called 'incontinence' is caused by having to wait for help to go to the toilet, people who are helped to eat in the most insulting and disrespectful manner, who are talked about in front of them as if they are not there, who have decisions made for them, who are treated as if they are not full human beings.

I have met people whose 'right to liberty' is curtailed by a lack of transport, drivers and escorts, who cannot choose to meet friends, go to the cinema, go for a walk round the block.

I have met people who experience no 'respect for their private and family life', whose mail is opened, who are denied the opportunity to have sexual relationships, who are separated from their families.

I have met people who are denied 'freedom of thought' and 'freedom of expression' because they do not have access to the support they need to communicate. This is perhaps the most fundamental denial of human rights because if someone is denied communication they are denied the opportunity to make choices, denied the most essential human interactions.

Independent living - as defined and campaigned for by the disabled people's movement - is not an optional extra. It is about promoting and protecting people's human rights. This is the most important thing that any social movement, any individual, can do. Let's hope we continue the progress we've made in the last decades of this millenium into the next millenium.

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