

# **WHY WE NEED A LEGAL RIGHT TO INDEPENDENT LIVING**

Gerry Zarb, Disability Rights Commission, UK

Keynote paper presented at European Congress on Independent Living, Arona, Tenerife, 24<sup>th</sup> to 26<sup>th</sup> April 2003

## **Introduction and background**

The paper examines some of the barriers disabled people face in trying to access support to make independent living possible. The paper discusses the possibilities for establishing legal rights to independent living and outlines the policy and campaign work that is being carried out by the Disability Rights Commission (DRC) in the UK.

First, some background information about the Disability Rights Commission.

The Disability Rights Commission operates throughout the UK. The organisation's main task is to address discrimination against disabled people in all its forms, through advice and conciliation, campaigning and legal enforcement. The DRC was created by the Disability Rights Commission Act (DRCA)1999. Section II of the Act imposes the following duties on the Commission:

- To work towards the elimination of discrimination against disabled persons;
- To promote the equalisation of opportunities for disabled persons;
- To take such steps as considered appropriate to encouraging good practice in the treatment of disabled persons;
- To keep under review the workings of the Disability Discrimination Act (DDA) 1995, which is the main piece of anti-discrimination legislation for disabled people in the UK.

The Commission's overall strategic objective is to bring about a

society in which all disabled people can participate fully as equal citizens.

A lot of the Commissions work is taken up with dealing with specific acts of discrimination that are defined by existing laws. But our remit also includes identifying and challenging other forms of discrimination and exclusion - including those that, at this point in time, have no legal remedy. Barriers to independent living currently fall into this category.

### **Why independent living is a rights issue**

There is little understanding (outside of the Independent living movement itself) that independence could, or should be, established as a basic and universal human or civil right. Even in countries like the UK where there has been considerable expansion in availability of resources like direct payments, access to independent living is still essentially granted on a discretionary, rather than mandatory basis. There are also considerable restrictions on both the levels of resources people can receive, and on the ways in which they are allowed to use these resources to organise their support systems.

One of the main reasons for these restrictions is that removal of all the of the barriers to disabled people's full social and economic participation requires practical action across a variety of social and economic sectors such as education, transport and employment. Public support systems on the other hand typically have great difficulty linking all of these actions together and, instead, tend to have different administrative functions to deal with them separately.

So for example disabled people might be eligible to receive services to enable them to access personal assistance at home, but not at work. Similarly, assistance with travel might be available for certain activities (going to school or to the shops, for example), but not for participation in social or leisure activities. In practice this often means that, instead of being able to participate freely in the full range of community life, disabled people have to organise their lives around whatever kinds of practical support are available. This might tackle some of the practical barriers they face but rarely all of them. And, in a lot of cases, the minimum support people can expect to receive does not guarantee much more than simply

being able to stay alive.

This almost universal problem is not just about the inefficiency of public support systems. More important still is the issue of controlling public expenditure and the negative impact this has on older and disabled people. Put crudely, removing all of the barriers to disabled people's full social and economic participation is considered to be simply too expensive when compared to meeting the costs of other social and economic priorities. In practice, this means that needs are defined by what public support systems are able, or prepared, to afford rather than by the actual barriers that disabled people face in their day to day lives.

In the UK, for example, eligibility for community care is mainly determined by the level of risk to people's independence. Assistance is only guaranteed if there is a substantial risk to people's health or functioning (if someone is unable to feed themselves for example). Anything beyond that is largely dependent on availability of resources and the spending priorities of different local and regional administrations (some of whom, to be fair, are much more progressive than others in terms of promoting independent living).

As a result, practically all of the existing support systems place some kind of ceiling - either in terms of cost or eligibility criteria, or often both of these - on the level of resources at which independent living is considered to be cost-effective. This means of course that people for whom independent living is considered to be too expensive are faced with a stark choice between struggling to maintain their independence in the community, or entering institutional care. Effectively, this amounts to putting a price on people's freedom. The Disability Rights Commission fully supports the Independent Living Movement's belief that this is a totally unacceptable abuse of people's fundamental human rights.

There are numerous ways in which disabled people are discriminated against as a result of not having any basic rights to independent living. These are just a few examples.

- Enforced admission to institutions and cuts in services:

There are very few places in Europe where disabled people have any guarantees about being able to live in the community. In the

UK for example, there has recently been an increase in reports of disabled people being threatened with enforced admission to institutional care as a result of cuts in social services budgets and the limits this places on public expenditure on disability services.

As budgets come under pressure some local administrations are also raising the threshold for eligibility for services with the result that, in some cases, disabled people are being denied access to essential support for basic activities like washing and eating. For example, in one case the Disability Rights Commission has dealt with in the past few months, disabled people were told that they could only be guaranteed to have a bath or shower once a fortnight and, even in then, only if there is a substantial risk to their health.

The Disability Rights Commission believes that eligibility for services should be based solely on needs, not costs and resources. It cannot be right for anyone in a civilised society to be denied such basic needs like being able to wash.

- Denial of opportunities for training and employment

Opportunities for economic participation are an essential part of independent living. However there are many examples of people being prevented from participation in training or employment as a result of not having access to personal assistance or other resources necessary to maintaining independence. Again, this is as much to do with a failure to understand what independent living is supposed to be about. For example, in the UK, as in many other countries, disabled people do have various entitlements to practical assistance at work. They also have varying degrees of protection against discrimination in employment. But, if you are not guaranteed the support you need to get up in the morning so you can actually get out to work, these rights are in reality of limited use.

- Discrimination in access to direct payments and personal assistance

Direct payments to arrange personal assistance are also an absolutely crucial resource for enabling independent living. However, there is significant inequality of access to direct payments on the grounds of discriminatory assumptions about

disabled people's capacity to manage their own affairs and the lack of any rights to support systems for people who need assistance to manage their own support arrangements.

- Denial of access to advocacy and communication support

There are very few rights for people who require assistance with communication. Similarly the provision of advocacy to enable people to make real choices about what services they receive and how they are delivered is almost always on a purely discretionary basis. Often the people who most need this kind of support are the least likely to get it.

The Disability Rights Commission believes that all disabled people should have a right of access to advocacy if they need it. All disabled people should also have a right to support to meet their access, information and communication needs. These services are not only vital for maximising opportunities for independent living. For many disabled people, they are also essential to enable them to exercise their basic human and civil rights.

- Denial of the right to receive appropriate health care

Access to appropriate health care when you need it is also vital to enabling independent living. However, a combination of physical, organisational and attitudinal barriers mean that many disabled people have restricted access to basic health care facilities. For people who are assumed to have limited capacity there is further discrimination in terms of compulsory treatment that, again, can often mean people being forced to go into institutions against their wishes.

Most serious of all perhaps is that disabled people are sometimes denied essential health care because of the medical profession's judgement about the value and quality of disabled people's lives. In many countries there is no legal protection against this happening and the consequences in far too many cases can - quite literally - be fatal.

- Attitudinal barriers

A related problem is that disabled people's aspirations for independence are too often undermined by over-protective or

negative attitudes about disability amongst both service professionals and the general public.

Most disability services are based on the belief that disabled people are 'vulnerable people' who need to be protected and 'cared for'. This is extremely damaging to the development of independent living as it only serves to reinforce perceptions of disabled people as passive 'recipients of care', rather than active citizens facing practical barriers to participation in the social and economic life of the community. By refusing to acknowledge any other legitimate role for disabled people in society, such beliefs are also discriminatory.

- Regulation

Discriminatory attitudes about the value of disabled people's lives are further reinforced by other areas of policy and legislation such as the European Commission's health and safety regulations and the various forms of Mental Health legislation adopted in different European countries. For example, much of the existing legal and policy framework for social care adopts a particularly restrictive approach to the assumed 'vulnerability' of disabled people and the potential risks, either to themselves or others, which are presumed to be associated with extending independent living. Again, in many cases, this effectively provides a legal justification for denying disabled people's rights to independent living.

Faced with the evidence of these kinds of examples it seems strange, to say the least, that we should even need to be discussing a right to independent living. Future generations are likely to look back on this and wonder why such abuses weren't outlawed long ago and why civilised societies were seemingly so content to exclude such a large number of citizens from the life of their communities.

But, we do not have to - and indeed we cannot - wait for some future utopia in order that all disabled people can have the freedom to live independent lives as full and equal citizens. The denial of people's rights to independent living can, and must be, challenged now.

### **The campaign to establish a legally enforceable right to independent living**

It was against this background that the Disability Rights Commission has recently started to develop a programme of work on establishing a basic enforceable right to independent living in the UK.

In 2002 the Disability Rights Commission formally adopted the following general policy statements in relation to independent living:

**"There should be a basic enforceable right to independent living for all disabled people.** Policy objectives for social care services need to include guaranteed minimum outcomes, backed up by a right to independence. The provision of social care must extend beyond functional 'life and limb' support to include support to enable participation in social and economic activities.

**All social care support services should be based on the principles of independent living.** All organisations commissioning and providing services should be aware of the social model of disability and be fully committed to delivering services that enable choice, control, autonomy and participation."

(Source: DRC Policy Statement on Social care and Independent Living, August 2002)

For the Disability Rights Commission, the term 'independent living' means disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. Any barriers to independent living can therefore be viewed as having a direct bearing on disabled people's freedom to exercise their human and civil rights. In other words, full participation and inclusion can and must be built on the foundation of independent living.

### **Next steps**

Establishing an enforceable right to independent living is a long-term objective that could take 3 to 5 years, or maybe even longer, to achieve. As a first step to meeting this objective the Commission has started work on gathering evidence to highlight

existing barriers to independent living, and how this impacts on disabled peoples' ability to exercise other rights. This evidence will be used to support the case for an enforceable right to independent living.

During the next year we also intend to start examining the broad legislative and policy options for establishing an enforceable right to independent living, including the kinds of barriers to independent living that need to be legislated on and the legislative options that might be the most fruitful to explore further. This might be by making changes to existing community care legislation at national level, for example, or using the provisions in the Human Rights Act, or it might mean completely new forms of legislation at either national or European level.

Work in subsequent years (2004 onwards) will concentrate on the following objectives:

- Establishing a consensus among about how 'independence' should be defined as a legal concept that embraces all groups of disabled people.
- Working up detailed proposals for translating this legal concept of independence into practical and enforceable rights.
- Campaigning and lobbying to seek adoption of the necessary changes to legislation.

### **Key challenges and opportunities**

There are going to be many obstacles to overcome before the right to independent living is a reality for all disabled people. There are also opportunities for challenging the denial of this right, and these must be used as much as possible.

First, one of the most important challenges will be to overcome the differences in people's understanding of what independent living means, and why it is so important.

We need to be clear that, when we talk about disabled people having a right to independent living, this means all groups of disabled having the right to whatever kind of support they need to make their independence possible.



This also means that we have to adopt a truly inclusive definition of independent living. Different individuals and groups need different kinds of practical support to achieve freedom, choice and control. For example, access to communication support for deaf people and advocacy or supported decision making for people with learning disability is just as essential to achieving independent living as personal assistance. Any definition of independent living that does not explicitly acknowledge the different ways that disabled people define and achieve independence will not be fully inclusive.

Second, although making the concept of independent living broad enough to embrace all disabled people has many positive benefits, it also creates new challenges. The biggest challenge will be to find ways of transforming and extending existing models of independent living without diluting the essential philosophy and principles on which it has been built.

For example, the concepts of choice, control and self-directed personal assistance have not always been seen as relevant to people with learning disabilities or mental health problems as they have to other groups of disabled people. Making choice and control possible for these groups would mean that the concept of independent living needs to be broad enough to include different ideas about things like how we define capacity for decision making and the role of advocates in enabling people to communicate their own choices and aspirations.

There are also challenges associated with the extension of independent living options to older people as we are seeing for example in the UK. Again, some groups of older people will have slightly different ideas about what independence means to them, and how they want to achieve it. This could create new opportunities for building alliances but there are also concerns about the possibility of diluting the concept of independent living if the boundaries are extended too far.

Another important challenge we are going to face is how to find the right kind of legislation to support a right to independent living for all disabled people.

There will almost certainly need to be changes to legislation at the

national level and the precise form that takes will obviously vary from country to country. However in order to make this possible we first need to establish the general principle that independent living is a basic and universal human and civil right.

One vehicle that offers positive potential for establishing this principle is the European Convention on Human Rights. In the UK we have recently seen some success in using the Human Rights Act to support disabled people's right to independent living which gives a great deal of positive encouragement for the future.

For example, in one case recently supported by Disability Rights Commission, the courts ruled that organisations providing community care services must take proper account of people's dignity, independence and human rights and respect their "rights to participate in the life of the community". Another landmark case last year concerned a woman who, because of unsuitable housing could only use the downstairs rooms in her family home. In this case the courts ruled that the local authorities failure to provide adequate housing adaptations created a breach of her right to privacy and family life under the Human Rights Act.

These cases are potentially very encouraging. In its present form the scope of the Human Rights Act is nowhere near broad enough to fully protect people's right to independent living, but cases like this can go a long way towards establishing the case for such rights. As we have seen in the UK, the Human Rights Act can also help to establish benchmarks about what degree of independence disabled people have a right to expect, and to highlight deficiencies in national legislation that can be used as basis for lobbying and campaigning.

### **Closing comments**

How we achieve the right to independent living is a fundamental issue, which needs to be considered very carefully. One of the most important tasks - which this Congress can help to achieve - will be to build and maintain alliances and partnerships to make sure that any proposals that are developed are fully compatible with the aspirations of disabled people generally, and the independent living movement in particular.

The most important challenge of all will be to develop a clear understanding - among both decision-makers and the general public - of what independent living means and why it is important.

For example, we need to question why, in the 21st century, it is still seen as acceptable for disabled people to be living in institutions against their wishes, to be denied access to basic support to enable them to enjoy a family or social life, and to be guaranteed no more than the bare minimum services necessary for day to day survival.

Finally, we need to win the argument that independent living is a basic universal human and civil right. Only then will it be possible for all disabled people to participate fully in the social, economic and civic life of the community.

For further information on the Disability Rights Commission's work on the right to independent living visit the DRC website:

<http://www.drc-gb.org>