

From Paupers to Citizens: Independent Living and Human Rights

Gerry Zarb
Head of Health and Independent Living Strategy
Disability Rights Commission, UK

Introduction

In this short paper I want to examine the relationship between human rights and independent living for older and disabled people in the context of current reforms in public services and the future equalities agenda. The paper focuses in particular on the extent of exclusion that older and disabled people face as a result of limited rights to independent living. It also examines the prospects for achieving legally enforceable rights to independent living and promoting Independent Living as a human and civil rights issue, particularly in the context of the forthcoming Commission for Equality and Human Rights.

What is Independent Living and why is it a civil and human rights issue?

I want to start off by explaining briefly what we mean by the term 'Independent Living' and why the DRC and others believe it is central to making a reality of disabled people's civil and human rights. I'll come on to the formal definition shortly - and you can read all about it at your leisure anyway in our recently published discussion paper, copies of which are available on the DRC stand.

But, before that, I want to tell you a story that I hope will illustrate very clearly exactly the sort of problems that older and disabled people face and why we believe rights to independent living are the solution.

I don't know how many of you are married, or have long-term partners - probably quite a few I would guess. I have a partner of nearly 15 years who I love very much, who is my best friend, my advisor, and who looks after me when I am unwell, as I do her. We have been together for quite a few years now, but nowhere near as long as my partner's parents who - like many of their generation - have clocked up more than 60 years of marriage so that it seems impossible to picture them as anything other than an indivisible partnership.

In reality I know that nature dictates that one day they will be separated, as will my partner and I. Death is always extremely sad and sometimes very

cruel in the way that it arrives. But it is unavoidable so we just have to prepare for the separation it brings as best we can.

Imagine for a moment though if we had the power to hasten that separation; to take partners away from each other after more than 60 years of marriage; in effect, to sentence their partnership to a heart-rending 'living death'.

What could possibly justify the legal exercise of such a power?

How about being sent to prison? Unfortunately, yes - even though one of the partners may be entirely innocent of any wrongdoing.

Terminal illness requiring permanent hospitalisation perhaps? It's arguable that this could be avoided by access to palliative care at home. But unfortunately that isn't always practical so, however sad, it's difficult to portray separation on such grounds as infringing any fundamental rights.

Another reason might be that one of the partners does not meet the criteria for support from public services such as housing or social care. But surely, that's just a technicality. No fair minded, democratic, society would sanction use of such a power.

True this was a regular occurrence in the Poor Law era when pauper families were regularly split up for no other reason that they did not meet the criteria for being supported by the parish. But in the 21st century? Surely not. Surely, common sense and basic compassion would override the use of such power. After all, we have human rights now don't we? We don't treat our citizens like paupers any more - or do we?

Regrettably, as the recent story of the Cheltenham couple, Beryll and Richard Driscoll shows - we have not managed to rid ourselves of the legacy of the Poor Law just yet.

As reported in The Guardian last month, the couple had been separated for the first time in 65 years because social services refused to put them in the same care home.

Burma veteran Richard Driscoll cannot walk unaided and relied on his wife to help him get around, while Beryll Driscoll is blind and was accustomed to using her husband as her eyes. But they have been forced to spend the last seven months apart. A place in a care home was found for Mr Driscoll after he fell ill but social services will not pay for his wife to stay with him. She is having to be looked after by other relatives and the couple, both 89, meet only twice a week.

Mrs Driscoll said: "We have never been separated in all our years together and for it to happen now, when we need each other so much, is so upsetting. I am lost without him - we were a partnership.

"It has been such a struggle without him. He was my eyes. Since I went blind 16 years ago he has done everything for me. I am so depressed. I just want to be with Richard but I am told I don't fit the criteria. I think it is very cruel."

And, as one of their sons has said:

"They had a great passion for each other, which makes me so angry that they have been torn apart. A lot more compassion should have been shown towards them both."

Indeed! This isn't Thomas Hardy's 1830s Wessex, nor Charles Dickens Victorian London - this is in Gloucestershire 2006. So how can it be that one of our most basic human rights can be overridden in this way?

There is nothing unique about Gloucestershire social services and - technically - they have done nothing wrong. Indeed, the professionals involved in the case were very sensitive to the anguish that the decision had caused and I'm glad to say that Richard and Beryll are in fact together again today and their 7 month ordeal is, for now at least, at an end.

But, even the fact that they have been reunited displays the fundamental problem with our current public support services as that has only been possible through another bureaucratic technicality, rather than by virtue of any inalienable human or civil rights.

As outlined in our discussion paper on independent living, there are a number of fundamental problems with the existing legislative framework for social care:

1. The framework places duties on local authorities to provide services, rather than giving rights to individuals to receive support. If it had been the other way round then clearly the starting point for Richard and Beryll's assessment would have been how to support them to stay together.
2. There is no entitlement to live at home instead of in institutional care. Again, if we had such rights it would have been impossible for Richard and Beryll to become separated in the first place.
3. It does not adequately cover assistance to participate in leisure activities, work, relationships, or looking after children/other family members. In the Driscoll's case, clearly the system failed completely to support their right to family life for example.
4. There is no legal entitlement to advocacy except in very limited circumstances.
5. Enforcement of existing entitlements involves negotiating an inaccessible legal system with inadequate support. It is stating the obvious that the Driscoll's would clearly have benefited greatly from being able to access

appropriate independent advocacy to help them negotiate their way through the system that forced them apart.

So, what is Independent Living and why is it the solution to these problems?

While there are numerous variations in the way Independent Living has been defined, they all tend to focus on four key values, namely choice, control, freedom and equality.

As Camilla Parker's recent analysis has shown there are several points of overlap between independent living principles and the key values of dignity, autonomy, equality and solidarity, or participation, which underpin human rights.¹

These values are all reflected in DRC's formal definition of independent living, based on principles defined by the Independent Living movement, and which has been adopted wholesale in the Prime Minister's Strategy Unit 2005 report on Improving the Life Chances of Disabled People:

"The term independent living refers to all disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations and should address the practical barriers to participation that they face."

Even if they do rely on support in their day to lives, this should not define the parameters of disabled people's identities, or the extent of their rights. In reality, disabled people are customers, workers, students, parents, taxpayers and voters, and community members. The purpose of any form of support should, therefore, be to enable people to overcome the practical barriers they face to participating in all of these roles and activities.

The DRC believes that there should be a basic enforceable right to independent living for all disabled people. Although some people assume that this already exists, the DRC knows it does not – and that many, many disabled people are denied independence on a daily basis. That is why we are supporting Lord Jack Ashley in introducing an Independent Living Bill in the current session of parliament aimed at establishing legal entitlements to a range of support, including advocacy and communication support, that we believe to be essential to enable disabled people to participate in the social and economic life of their communities on a par with other citizens.

The extent of disabled people's exclusion

¹ Camilla Parker, *Independent Living and the Human Rights Act 1998*, DRC/NCIL/SCIE, December 2004

The over-arching goal for establishing rights to independent living is to create a level playing field by entitling people to a minimum level of support necessary to participate in the range of social and economic roles and activities that most citizens take for granted. Even the most cursory examination of the evidence on the extent of disabled people's exclusion can leave no doubt as to the justification for such rights.

Disabled people have very few rights to services that would guarantee assistance to enable independent living. What minimum rights there are do not guarantee very much more being washed and fed.

A particularly important issue for DRC is that of enforced or inappropriate institutionalisation. While there is no central monitoring on this, there are numerous anecdotal accounts from organisations such as NCIL of people who are either stuck in residential care or afraid of being forced into residential care, because of rigidly applied budget rules in their locality. They include a woman in her early twenties, wanting to get on with her life, who can not get out of residential care because her estimated care package is £80 a week more expensive than a local care home. Also, the case of a woman more than 100 years old, wanting to end her life in her own home, who can not stay there because her estimated care package is higher than the costs of a placement in a care home.²

And we read about other ways of restricting people. People with learning difficulties and a label of challenging behaviour, sent to a privately run residential institution, where they will be locked in, shielded from the outside world and utterly isolated from it.

These individuals can not exercise their ordinary human rights; can not participate in daily life on a basis of equality. Independent living support, including advocacy, would enable them to change their situation.

There are no positive rights in existing legislation to enable people to choose where they live or who with and no legal protection against disabled people being forced to live in institutional care against their wishes. Nor are any such rights proposed in the recent white paper on the future of health and social care. Indeed, a specific proposal for such a right from DRC has, so far at least, been resisted by the Department of Health. It will nevertheless feature as one of the key proposals in the Independent Living Bill.

It is difficult to square this response with the rhetoric of government's 'choice and voice' agenda. Surely it is neither fair nor logical that statutory care standards make it mandatory for people to have a say over things like what colour paint they have in their room in a care home, yet gives them no rights to say whether or not they want to live there in the first place.

The British Government's lukewarm approach to institutionalisation is in marked contrast to the situation in the US where the Olmstead ruling by the

² Information supplied by National Centre for Independent Living

Supreme Court decreed that forcing people to live in institutions is a form of disability discrimination and ordered that federal states had to pay for IL support.

Another very important way that rights to independent living could underpin older and disabled people's ability to exercise their civil and human rights is by tackling head on the state of institutionalised dependency that our current public services often do more to maintain than to challenge.

Common perceptions of the nature and purpose of social care - among both service professionals and the general public - essentially portray 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.

Indeed, it is very telling that policy and practice has traditionally been placed under the nomenclature of 'care' rather than 'support'. The difference between the two is much more than a matter of semantics however. The way in which the essential purpose of public services is defined has a huge practical impact on how those services are organised and delivered and, consequently, the kind of outcomes people can expect to receive. Outcomes based on care tend to maintain and reinforce dependency. Outcomes based on support, on the other hand, clearly imply an expectation of participation and active citizenship.

In his recent speech 'Achieving equality and social justice – a future without disability?', the DRC Chairman, Bert Massie, highlighted how, despite recent developments such as the Disability Discrimination Act:

"Society still sees its best response to disability as care, welfare and charity - rather than equal rights, opportunities and citizenship ... Our instinct is to protect. But in 'protecting' people we deny humanity rather than liberating it.

And in order to protect we can make people dependent. To borrow from Amnesty International's new campaign, we need to 'protect the human' by extending freedom, respect, equality and dignity."

The Prime Minister's Life Chances report made a similar point:

"Historically, disabled people have been treated as being dependent and in need of 'care', rather than being recognised as full citizens."

The result of this deeply embedded dependency culture is that policy and practice on supporting disabled people's participation and inclusion is becoming increasingly out of synch with the modernising aspirations that characterise the current political agenda. It might well be that disabled people have moved from being 'undeserving' to 'deserving' paupers in the slightly more benign 21st century manifestation of the Poor Law, but they remain paupers all the same.

As society has come to expect disabled people to accept the ordinary obligations of citizenship, for example to work or to be good parents, so a new light has been cast on existing systems of entitlement and support which are failing adequately to provide disabled people with the means to do so.

This gradual realisation has coincided with wider debates concerning public sector reform which emphasise extending greater choice and control to all citizens over the design, delivery and evaluation of services.

Such an approach to public service delivery has been pioneered through 'direct payments' to users of social services, with evidence of mutual benefits to both service user and provider, including a more effective and efficient use of resources over time.

However, there remains a persistent culture of categorising some disabled people as inherently 'vulnerable', at risk and without sufficient competence to manage their own affairs. When combined with public authorities' 'duty of care' and a culture of risk aversion in areas of the public sector, opportunities for disabled people to assume greater control over their own lives too often remain extremely restricted.

Human Rights, Independent Living and Equality

In the final part of this paper I want to consider how the Independent Living and Human Rights frameworks might interact and reinforce each other and the prospects for using both as tools for promoting equality and citizenship.

Section 6 of the Human Rights Act 1998 requires all public authorities to act in a manner that is compatible with the European Convention on Human Rights. But the HRA is not just a legal mechanism. It is also intended as a tool for promoting a culture of respect for human rights.

With that aim in mind DRC, working with SCIE and NCIL, recently commissioned Camilla Parker to explore how the HRA could be used to influence practice compatible with promoting rights to Independent Living.³

Her analysis identified a number of ways in which independent Living, human rights and public support systems - particularly social care - can be linked in practice.

First, independent living can be seen as essential to enabling disabled people to fully exercise their human rights: For example, disabled people living in residential care homes will face a range of restrictions on their private and family life and their opportunities to engage in society.

³ *Camilla Parker, Independent Living and the Human Rights Act 1998, DRC/NCIL/SCIE, December 2004*

This is a particularly important issue for DRC because, while there has been an overall decrease in the rate of permanent admissions to residential and nursing care, for some groups of disabled people - particularly people with learning disabilities and mental health conditions - the numbers are still on the increase.

There are also important questions to be asked about the potential incompatibility between institutionalisation and protecting people's psychological integrity, as required by the HRA.

Secondly, Independent Living is a process of empowering people to exercise their human rights: Ensuring that disabled people can live 'ordinary' lives provides them with the opportunities to exercise their rights. Independent living is an important means of enabling people to access their human and civil rights.

Thirdly, the failure to respect human rights has an adverse impact on Independent Living. For example, a routine of providing breakfast to residents while they are sitting on their commode has a severe impact on the individuals' independence, dignity and autonomy. Again, there also questions to be asked about whether such practices are compatible with the principle of protecting people's psychological integrity.

In practice however current policy and practice on meeting older and disabled people's support needs does not adequately reflect either the spirit or the legal requirements of the European Convention on Human Rights (ECHR). With the exception of the Bournemouth judgement legal cases that have highlighted Human Rights failings in existing community care arrangements (e.g. East Sussex and Enfield) have not resulted in any corrective measures in either legislation or statutory guidance.

As Help The Aged have highlighted in relation to older people - although their findings apply equally to disabled people - the very system by which support is currently organised and delivered can actually put people's human rights at risk.

For example, eligibility for support is often so tightly rationed that people are left in deteriorating circumstances until such time that their situation is deemed critical enough to warrant support. Similarly few services go beyond very basic 'life and limb' support to address the range social, psychological or emotional needs, which may be essential for sustaining the level of dignity and integrity required by the ECHR.⁴

Most importantly perhaps, as the story of Richard and Beryll Driscoll so graphically illustrates, people's rights to respect for private and family life under the ECHR are completely overridden when they are required to leave their homes and families against their will - either because they do not meet

⁴ Tessa Harding, *Rights At Risk: Older people and human rights, Help The Aged, 2005*

local eligibility criteria or because it is deemed more cost effective to place them in residential care rather than provide adequate support at home.

The HRA has, so far, been little used for cases related to independent living specifically (with the major exception of the *Botta vs Italy* case). However as we have already heard, recent cases in the UK have shown encouraging signs of the potential for using Convention rights in ways that are supportive of at least some important elements of independent living.

For example, in the recent lifting and handling case supported by DRC, the high court ruled that organisations providing community care services must take proper account of people's dignity, independence and human rights under the Convention. In particular the court ruled that the way services are delivered must respect their "rights to participate in the life of the community". Another landmark case, in *Enfield*, 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 authority's failure to provide adequate housing adaptations created a breach of her right to privacy and family life under article 8.

It is hoped that these developments can be built on in the future.

On the broader horizon, we have the revised European Social Charter which at Article 15 provides for the 'independence, social integration and participation in the life of the community' of disabled people. Although still some way off, there is also the Draft UN Convention with its principled insistence on independent living and participation.

On the domestic front, of course, there are now just 18 months before the Commission for Equality and Human Rights opens its doors for business. The duties of the new commission will include:

- Encouraging awareness and good practice on equality and diversity
- Promoting awareness and understanding of human rights
- Promoting equality of opportunity
- Working towards eliminating unlawful discrimination and harassment
- Promoting good relations between different communities
- Keeping discrimination and human rights legislation under review

The Disability Rights Commission welcomes the Equality Bill, which establishes the new Commission. It marks a new approach to equality and human rights, which we believe has great potential to transform the life chances of disabled people and other marginalised groups in our society

As DRC's Legal Director - Nick O'Brien - has pointed out, the Equality Bill marks a sea change in the approach to tackling discrimination. The new Disability Equality Duty switches the focus from individual acts of discrimination to the positive actions that public bodies need to take to tackle discrimination, and to promote equality at an institutional level.

He further argues that this new duty takes us way beyond existing anti-discrimination legislation in that, rather than simply aiming to level an uneven playing field, the duty explicitly recognises the need to take positive steps to remove barriers to participation and inclusion:

"the refusal to acquiesce in equal treatment and the willingness to transcend that limited strategy by insisting on 'going the extra mile' (as it were) to make the positive interventions that will actually deliver substantial equality of outcome rather than merely formal symmetry." ⁵

Concluding comments

Achieving independent living demands a universal refocusing of public policy and services towards the goals of promoting choice, control and participation amongst disabled people. This will require the commitment and shared action of different national and local government departments, and shift in culture which moves on from categorising disabled people as inherently vulnerable and which allows the sharing of risk between service users and providers.

Applying human rights principles to the question of promoting independent living and inclusion also highlights the need for some significant changes in the ways we have traditionally viewed provision of support for disabled people. For example:

- Promoting community living in place of institutional care.
- Providing support which facilitates social inclusion and participation.
- Ensuring that the delivery of social care and other support services maximises choice and control.
- Accepting that the ultimate aim of any support system should be to address barriers to social inclusion and participation.

In particular, 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 for day to day survival.

For all the apparent complexity in achieving independent living, its goals are fairly unremarkable. It is essentially about disabled people accessing the freedoms and life opportunities they should expect as British citizens – nothing more and nothing less.

However, while independent living is already a reality for some disabled people, for many others it is a distant dream.

⁵ Nick O'Brien, *Accentuating the Positive: Disability Rights and the Idea of a Commission for Equality and Human Rights*, Industrial Law Society, St Catherine's College, Oxford, 10 September 2004

Having put in place anti-discrimination measures to remove the barriers and create a more 'open road ' for disabled people, the next step in the journey towards equal citizenship is to provide people with the more equal start that independent living represents.

For many, progress towards the goal of equality absolutely depends on it.