

CHAPTER 13

Independent Living and the Road to Inclusion

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Introduction

This chapter examines the significance of independent living to social inclusion, the links between independent living and the social model of disability, and the barriers to independent living that disabled people face. It also discusses independent living as a civil and human rights issue, and outlines the prospects for achieving legally enforceable rights to independent living for all disabled people.

The discussion is set in the context of the Disability Rights Commission's (DRC) ongoing work on establishing a right to independent living. The Commission is working closely with a wide range of disabled people and other organisations on trying to achieve this objective. These include the European Network on Independent Living and the National Centre for Independent Living. The DRC's overall

strategic vision is to bring about a society in which all disabled people can participate fully as equal citizens. A lot of the Commission's work is taken up with dealing with specific acts of discrimination that are defined by existing laws. But the DRC's 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.

In 2002 the DRC 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 (DRC 2002).

Why is independent living a rights issue?

The concept of independent living is a very simple

one, and mirrors the essential principles of the social model of disability. Basically, 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.

As Finkelstein (2001: 6) points out, the essential principle of independent living – that disabled people should have control over their own lives – was also central to the social model solutions to end exclusion and segregation proposed by the Union of the Physically Impaired Against Segregation (UPIAS) in the *Fundamental Principles of Disability* (UPIAS 1976). Following on from the basic distinction between the individual and social models of disability, UPIAS stated that:

disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (1976: 3).

Similarly, there have always been strong links

between the political organisation of the disability movement, its re-definition of the 'problem' of disability and the collective challenge to discrimination:

Indeed, it was the idea of independent living which gave a focus to the struggles of disabled people to organise themselves, initially in the United States and subsequently elsewhere, including Britain (Oliver 1996: 15).

There is little understanding (outside of the disability movement itself) however that independence could, or should be, established as a basic 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 (Zarb 1999; Morris 2004).

One of the main reasons for these restrictions is that removal of all 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 (Zarb 1995). 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 the actual barriers that disabled people face in their day to day lives (Zarb 1999, 2001).

Eligibility for community care, for example, is mainly determined by the level of risk to people's

functional 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 authorities (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.

Establishing independent living as a human or civil rights will of course mean much more than simply removing the barriers in existing support systems – although that objective remains absolutely crucial. Ultimately, even more fundamental rights of citizenship would need to be established in order to invert (or subvert) existing common sense understanding of disabled people's excluded and segregated position in society. The problematic nature of this challenge can be illustrated by consideration of how the concept of rights to independent living might compare to existing rights of citizenship, as these are commonly understood.

Existing debates about civil rights imply an important distinction between what might be called 'essential' and 'conditional' rights. Essential (or immutable) rights are those that relate to barriers which no reasonable person could view as acceptable as a normal condition of citizenship (such as the freedom to develop social relationships, and engage in family life). Conditional rights on the other hand relate to barriers which, potentially, all citizens might face at some point – albeit not necessarily as a consequence of disabling social structures, institutions, and attitudes. Examples include the restricted freedom of choice over type or location of housing or financial insecurity.

However, in reality, it is probably fair to say that very few rights of citizenship are unconditional in the sense that they are associated with guaranteed material outcomes. Thus, the Human Rights Act 1998 states that all citizens have the right to work but in practice that only confers a right of opportunity to work (not a guarantee that work will always be available). In the context of the right to independent living, the implication is that there might be a distinction to be made between rights to services, resources and other entitlements that enable equality of opportunity and equality of access and those that would, if enforced, guarantee certain material outcomes.

People who are not convinced about the need for a right to independent living might argue that, by advocating the social model of disability, we sometimes stray over the line between equality of

opportunity and guaranteed outcomes by advocating complete removal of barriers over and above those faced by all citizens. But, in some cases guaranteed material outcomes are essential precisely because of the fact that, without them, disabled people cannot have equality of opportunity or access. Obviously we could argue that things like personal assistance, facilitated decision making and the removal of material access barriers fall in to this category. But something like the right to a completely secure living environment might be less clear-cut on the basis that, arguably, this is not something that any citizen can be guaranteed.

Such equivocation is potentially very dangerous as it opens up the possibility of independent living being seen as a conditional rather than an essential right of citizenship. Full inclusion cannot be achieved without the level playing field that removing barriers to independent living would create. It is essential therefore that we are able to clearly demonstrate what the barriers to independent living are, as well as the practical impact they have on disabled people's lives.

Dependency, segregation and discrimination

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

i) *Enforced admission to institutions and cuts*

in services Disabled people have very few guarantees about being able to live in the community and there is no legal protection against people being forced to live in institutional care against their wishes.

Indeed, despite an overall slowdown in the rate of permanent admissions to residential and nursing care, for some groups of disabled people, the numbers are still on the increase. Between 1997 and 2002 the number of people with physical and sensory impairments in local authority supported residential and nursing care showed a modest decrease from 10,356 to 9,755. For people with learning disabilities, on the other hand, there was an increase of nearly 20 per cent from 25,446 to 30,345 while the figure for people with mental health problems rose by more than 40 per cent from 7,965 to 11,275 (Department of Health 2003).

There has also 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 DRC 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 then, only if there is a substantial risk to their health. There are also no guarantees about continuity of support if people want to move from one local authority area to another, which is a significant obstacle to social and economic mobility.

ii) ***Restrictions on 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, disabled people do have various entitlements to practical assistance at work as well protection under the DDA 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.

iii) ***Restrictions on 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.

For example, according to the latest full year figures, out of 7,882 people receiving direct payments only 736 (less than 10 per cent) are people with learning difficulties. The figures for mental health service users are even worse at only 132 (less than 2 per cent), with over 60 per cent of local authorities reporting no mental health service users supported via Direct Payments at all (SSI 2003: 37)

iv) ***Lack of rights 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 DRC 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.

v) ***Restricted access to 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. At present there is no legal protection against this happening.

vi) **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 fundamentally discriminatory.

vii) **Regulatory barriers** Discriminatory attitudes about the value of disabled people's lives are further

reinforced by other areas of policy and legislation such as health and safety regulations and Mental Health legislation. 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.

Negative attitudes linking risk and disability also impact on other aspects of disabled people's lives such as education. Cognitive or emotional impairments are often interpreted and labeled as 'behavioural problems' with the result that a need for social support is translated into a need for exclusion (Russell 2003). A recent study by the Audit Commission for example found that, in the 22 Local Education Authorities visited, 87 percent of exclusions at primary level and 60 percent at secondary level were of pupils with Special Educational Needs (Audit Commission 2002). Needless to say, this kind of response does little to enhance opportunities for independence and self-determination.

Transforming dependency

The pervasive categorisation of disabled people as 'vulnerable people' in the context of public support systems is a major obstacle to independent living.

Such categorisation is based on a reductionist and individual model of disability that is both muddled and damaging. It is muddled because external barriers are seen purely in terms of problems for individuals requiring atomised, individual solutions, thereby leaving the underlying structural source of disabling barriers unchallenged. This failure to link individual needs to structural barriers is both discriminatory and damaging because it effectively leaves disabled people in a state of dependency. It can be likened to a roundabout where services based only on partial solutions simply recycle dependency while at the same time closing off the exits that would re-route disabled people towards empowerment and inclusion.

As Finkelstein argues, there are clear parallels with the social model analysis offered by UPIAS in the context of reductionist responses to other kinds of barriers faced by disabled people, such as those related to exclusion from economic activity: We also felt, given the background of that time where the popular concern was to campaign for a national disability income, that this, incomes approach, is basically a compensatory approach. What people are asking is that disabled people, because they are disabled (because through no fault of their own they are impaired), should be provided with a statutory income to compensate for their personal defects – it's a compensatory approach. The UPIAS argument, however, was that the central issue is one of oppression not compensation. We don't want to be compensated for being oppressed! We want people to stop oppressing us! The logic of these different

perspectives is very simple. The former interpretation of disability places us in a permanently dependent relationship to able-bodied society for handouts – what we called state charity. The latter approach says that the able-bodied society's got to change, it's an oppressive society (Finkelstein 2001: 4).

The impact of this 'compensatory approach' to disability in the context of independent living can be illustrated very clearly by the process of assessment for community care services which is narrowly focused on personal 'activities of daily living' or 'self-care'.

From April 2003, local authorities in England are supposed to undertake assessments and reviews according to a unified set of criteria designed to evaluate eligibility for support based on the risk to people's independence. The new assessment guidance (Department of Health 2002) proposes that eligibility should be assessed according to the degree of 'risk' ('critical', 'substantial', 'moderate' or 'low') to a person's independence in terms of the following factors:

- *autonomy* – which refers to the extent of choice and control people have over their own lives;
- *health and safety* – for both disabled people and others;
- *managing daily routines* – including practical support people need to meet their responsibilities to family members or other

dependents;

- *involvement* – as well as involvement in work, education and learning, family life, social and community activities this also includes recognition of individual's broader social roles and responsibilities.

In theory, assessments should now look at all of these aspects of independence in the round and assess the degree of risk – both currently and longer-term – attached to failing to meet an individual's needs. However, the assessment process is also used as a rationing device and there is evidence indicating that, in practice, eligibility for support is only guaranteed when there is a 'critical' or 'substantial' risk to health or functioning (Prasad 2002).

So, for example, where failure to provide support would pose a risk to health or prevent somebody from carrying out 'vital' personal care or domestic routines, this would be defined as a 'critical' risk. Inability to maintain involvement in several aspects of work, education or learning, and/or social support systems and relationships, on the other hand, is classified as only a 'moderate' risk to independence. In an environment of competing resources eligibility thresholds tend to be set high, with the result that the overall balance between the various risk criteria remains heavily skewed towards a functional 'life and limb' approach. Factors such as health and safety and daily routine are given greater emphasis than autonomy and involvement in community life whereas, in reality, these are interdependent and are

all equally important to disabled people themselves.

As Morris points out, truly enabling assessment should be about human and civil rights:

Assessments should identify: what someone wants to achieve, and what is getting in the way. Instead of asking 'What is wrong with this person', a needs-led assessment asks 'What is wrong for this person?'

Assessments should ask: which human and civil rights are being contravened? Which need to be promoted, improved, or extended? (Morris 2002: 4-5).

The differences in approaches to assessment that Morris outlines echo the distinctions between dependency and independence and between compensating for and challenging exclusion. Developing support systems to enable independent living implies the need for a significantly different approach to assessment and the organisation of support systems focusing on barriers and outcomes that would enable disabled people to participate on the same basis as other citizens. However, as already discussed, there are significant barriers to achieving the kind of root and branch transformation that meeting this objective would require. The final part of this chapter examines how this challenge

could be met.

Prospects for achieving a right to independent living

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 pursued if full inclusion is to be achieved.

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 covers all groups of disabled having the right to whatever kind of support they need to make their independence possible. It 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 difficulties 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 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, concepts like choice, control and self-directed personal assistance

- – both in the way they have been conceptualised and applied in practice
- – have not fully embraced the needs and experiences of people with learning disabilities or mental health problems. 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 with direct payments. 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. At the same time, it is important to realise that making the concept independent living fully inclusive also demands a proper analysis of the ways in which disablement and

other forms of exclusion – particularly ageism – interact to enforce and maintain segregation and dependency.

A key issue will be to develop forms of analysis that can link disabled people's experience of discrimination and exclusion with the disabling institutions and processes that help to create that experience in the first place. We need to find a way of making visible the process by which subjective experience becomes a material and practical reality. There are already some pointers to achieving this goal, such as the work by Beresford and others on developing a social model of madness and distress, but this has yet to be fully integrated into the core activity of disability studies (Beresford et al. 1996; Beresford 2000).

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 existing legislation to secure specific rights to resources that would enable independent living (a right to independent advocacy for example). 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 (Clements and Read 2003). In the UK we have recently seen some success in using the

Human Rights Act 1998 to support disabled people's right to independent living which gives some positive encouragement for the future. For example, in one case recently supported by the DRC, 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 in 2002 (Bernard vs. London Borough of Enfield) involved 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 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 a basis for lobbying and campaigning.

Are rights enough?

The discussion in this chapter explicitly links the right to independent living with general and universal citizenship rights. But it is debatable however whether

legalistic remedies on their own would be sufficient to overcome the denial of citizenship rights experienced by disabled people.

First there are reservations about the efficacy of anti-discrimination legislation generally for the most excluded groups (for example, people who have spent all or most of their lives in institutions). Because rights within the kind of legalistic framework provided by, for example, the Disability Discrimination Act 1995 are dependent on people having the necessary resources to exercise them, those who have the most to gain or who are in most need of legal protection are often the least likely to benefit (Zarb 1995). The deep-rooted (and often internalised) exclusion associated with institutionalisation and segregation may effectively disenfranchise whole groups of disabled people, thereby creating a hierarchy of access to any rights to independent living that may be achieved in the future.

Second, some commentators (Finkelstein 1999, 2001; Oliver, 2001) have questioned whether any solutions that are, essentially, based on individualised rights can be seen as compatible with the social model of disability and the collective emancipation of disabled people. One of the central arguments in this critique is that the civil rights approach is still, essentially, based on 'compensating' disabled people for the various forms of disadvantage and exclusion they face, rather than structural change aimed at removing the causes of exclusion. As Finkelstein contends:

Since such disadvantages are no fault of its own, a 'caring' society, the argument goes, will humanely concede 'rights' and provide compensatory services and benefits. This not only frees people with abilities from all responsibility for our predicament but the compensatory approach encourages a feel good-factor for being charitable. A complete inversion of social reality! Indeed this illusion about what are in practice 'compensatory' civil rights being a big idea is so enchanting that even the disability movement has been captivated (much to the delight of politicians with abilities) into believing that civil rights can provide a platform for announcing our commitment to emancipation (2001: 8).

The dangers that this critique implies are very real and need to be addressed if independent living for all is to become a reality. As noted earlier, there are inherent dangers associated with a purely legalistic approach to citizenship as, once we start to legislate, the scope of what rights people can expect to receive immediately becomes open to both legal and political (and maybe even moral/ethical) challenge. As Sayce (2003) points out, the operation of the Americans with Disabilities Act 1990 has already demonstrated the potential problems with legalistic challenges. For some groups of disabled people at least, a combination of pressure from vested interests and lack of understanding about how different aspects of the legislation should be interpreted has resulted in a progressive narrowing of the scope of the law in the courts.

Critical Legal Studies theory would say that it is no surprise that a law has been narrowed and constrained in this way, because the drafting, interpretation and implementation of law are part of social discourse. For law to be an effective agent for social change requires it to be addressed in this context. Interventions are needed at the level of social discourse. Simply passing and enforcing a law is not enough. ... A lesson for Britain is that it is a major priority to influence public and political debate, informing people why disability rights are important and what they mean in practice. Otherwise, implementation of the law could become ever more limited by the definitions imposed on the debate by those with power to perpetuate discrimination (Sayce 2003: 632).

So, before we can even begin to consider the legal configuration of a right to independent living there is a much more fundamental challenge to transform the discourse that maintains disabled people in a state of dependency, and to develop a clear understanding 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.

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