

# The future of independent living

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## Introduction

The National Centre for Independent Living sees independent living as an essential component of disabled people being able to exercise their human and civil rights. So it makes sense for NCIL to work in partnership with a disability rights organisation, to press for a right to independent living.

The first part of this presentation outlines the Disability Rights Commission's approach to independent living and human rights. The second part looks at how NCIL is campaigning alongside the DRC to promote these rights.

## Independent living and the disability and human rights and citizenship agendas

The DRC believes that there should be a **basic enforceable right to independent living for all 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.

The Human Rights Act 1998 (HRA) requires all public authorities (which includes NHS Trusts and local authorities) to act in a manner which is compatible with the European Convention in Human Rights (ECHR) and allows individuals who claim that their rights have been, or will be breached, to take legal action against the relevant authority.

However the HRA is also intended to promote a culture of respect for human rights. Accordingly, public authorities should not be concerned solely with the avoidance of litigation, rather they should look to how the HRA can assist in the positive development of best practice. According to the Audit Commission, the HRA should mean that:

*'...service decisions would be made with reference to basic rights, such as the right to privacy and family life, the right to a fair hearing and the right not to suffer degrading treatment.... Managers would have a clear understanding of their obligations under the Act and carefully balance an individual's rights against those of the wider community when making their decisions.'*<sup>1</sup>

There are several points of overlap between the independent living principles and the HRA.

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<sup>1</sup> Audit Commission, *Human Rights: Improving public service delivery*, Audit Commission, London 2003, paragraph 1

Human rights are based on four key values – dignity, autonomy, equality and solidarity:

- **Dignity:** by focusing on the inherent dignity of the human being first, and subsequently (and only if necessary), on the person's medical characteristics, the human rights model places the person at the centre of all decisions affecting him/her. Furthermore the problem of the disability arises from the failure of society to respond to the difference that disability represents. Thus: *'...the State has a responsibility to tackle socially created obstacles in order to ensure full respect for the dignity and equal rights of all persons'*.
- **Autonomy:** This is based on the presumption that individuals have the capacity to take action for themselves – they can make their own decisions based on their personal conscience and freely made life choices. The human rights model 'is not over-inclined to detect incompetence' but where this is the case will provide effective protection for those that are not 'legally competent'. Furthermore, the model seeks to enable those who have capacity to make decisions for themselves to 'exercise their right of self-determination'.
- **Equality:** The core premise of equality is that 'all persons not only possess inestimable inherent self-worth but are also inherently equal in terms of self worth, regardless of their difference'. This gives rise to the 'ethic of "equality of opportunity"'. In the context of disability this calls for tackling structural exclusion (transport etc) enabling people to take up socially responsible and productive roles (e.g. providing inclusive education) tackling discrimination (for example anti-discrimination laws) and implementing a coherent programme to address deep-seated attitudes about disability.
- **Solidarity:** The main purpose of this is to 'prime people for participation in all mainstream processes of society'.

Independent Living challenges the barriers to inclusion ('Dignity') and the assumptions about people's ability to make decisions for themselves and where people clearly have the capacity to make decisions for themselves, the failure to enable them to act upon their choices (Autonomy). Independent Living also means disabled people having the same opportunities as non-disabled people (Equality) and that disabled people can participate fully in all aspects of society (Solidarity).

The relationship between Independent Living, human rights and social care can be considered in a variety of ways.

- **Without independent living disabled people are not able to exercise all their human rights:** For example, disabled people living in residential care

homes will face a range of restrictions on their private and family life, such as less contact with their family and friends.

- **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. Thus independent living is '*a means to an end: it is a way of people accessing their human and civil rights*'. The provision of social care is a key factor in enabling people to live ordinary lives.
- **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.

A case supported by the DRC, in East Sussex, underlined this important point. Policies on lifting and handling were preventing two disabled women from exercising their right to participation. The judge ruled that their Charter rights must be respected, and could not be over-ridden by the health and safety concerns of the workers involved: a balance of rights has to be arrived at.

- **Independent Living as a specific right:** The Tenerife Declaration [ref, 2003] states '*Independent Living is a fundamental Human Right for all disabled people regardless of the nature and extent of their impairment*'. A specific right to Independent Living is required because while disabled people are entitled to the same human rights as non-disabled people they cannot benefit from such rights, unless additional requirements (arising from the impairment or from disabling attitudes and/or the environment) are met:

*'we have **additional requirements**, such as mobility needs, communication assistance, personal assistance, and so on. A legislative framework that confers human and civil rights will not be effective for disabled people unless we also have entitlements to these additional requirements'*. [Morris, 238]

## **How far do existing policies and practices fit with human rights?**

Jenny Morris has outlined 'five fundamental problems' with the current legal and policy framework for social care:

- *It places duties on local authorities to provide services, rather than gives rights to individuals to receive support*
- *There is no entitlement to live at home instead of in institutional care*
- *It does adequately cover assistance to participate in leisure activities, work, have relationships, or look after children or other family members*
- *There is no entitlement to advocacy*

- *Enforcement of existing entitlements involves negotiating an accessible legal system with inadequate support<sup>2</sup>*

## **The economics of independent living**

Getting to the future of independent living that we want to see means making more than just a rights based case for it. We believe there is a strong economic case for IL, too.

Outside of the independent living movement itself, public and professional understanding of independent living tends to be limited to thinking about disabled people only as users of support services. This is both factually incorrect and discriminatory.

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. This is why expenditure on independent living needs to be seen as a form of positive investment. Increased participation not only benefits disabled people themselves but also produces economic benefits to governments, businesses and communities.

Of course, economic considerations should not be the only justification for investing in independent living. There need to be alternative criteria for guiding public investment decisions - particularly those based on social justice and basic human and civil rights. One only has to think about a disabled person being forced into an institution on the grounds of cost savings to realise that the argument for a basic human right to independent living is - or at least should be - more than strong enough on it's own. If this can be combined with the force of economic persuasion then the call for all disabled people to have the benefits of independent living could become irresistible. Perhaps one day the question will no longer be, can we afford to invest in independent living, but can we afford not to.

## **Achieving rights to independent living**

The debate about the social and economic benefits of independent living is more than theoretical, it affects thousands of people on a daily basis. NCIL has been contacted several times this year by 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 women in her early twenties, wanting to get on with her life, can not get out of residential care because her estimated care package is £80 a week more expensive than the care home. A woman more than 100 years old, wanting to end her life in her

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<sup>2</sup> 429

own home, can not stay there because her estimated care package is higher than the care home costs.

A recent report on costs of living as a disabled person, by Disability Alliance, reveals a shocking level of unmet need. Deaf people have such inadequate access to communication support that their health care, their social lives, their education, even daily life such as shopping, are all restricted.

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.

## **The future of independent living**

So, with DRC and others NCIL is looking for a system that will:

- Promote community living in place of institutional care
- Provide support which facilitates social inclusion and participation
- Ensure that the delivery of social care maximises choice and control
- Address the barriers to social inclusion and participation

We are working to create a future in which disabled people:

- have the right to make genuine, informed choices about how their support needs should be met and should be fully involved in the planning and design of support services;
- can expect to be able to use support services that are based on the principles of choice, control, autonomy and participation;
- do not encounter discrimination or disadvantage when accessing services.

In addition there are some specific rights that are needed to make independent living a practical reality.

All disabled people should have access to advocacy if they need it. The under-provision of access to advocacy support needs to be addressed as a priority. Existing advocacy and information and advice networks need to be adequately resourced so that they can be fully utilised.

All disabled people should expect to be able to live in homes they can move around in, carry out their daily lives in, in privacy and in safety; in homes they can leave when they want.

All disabled people should have a right to support to meet their access, information and communication needs. Organisations commissioning and providing services need to be aware that, for many disabled people, social inclusion depends on having access to communication support and other assistive technologies, aids and equipment. Access to information about availability of, and entitlement to, services - as well as the means to use information effectively - is also vital to maximising opportunities for independent living.

Some of these aims can be met in the short term, others will take longer term planning and investment. For all of them, we need to start planning now, so the future comes a bit closer.