The Future of Independent Living

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November 2004

Introduction

The National Centre for Independent Living (NCIL) sees independent living as an important way for disabled people to use their rights. NCIL will work with the Disability Rights Commission (DRC) to make sure disabled people have a right to independent living.

Today we will:
- talk about how the Disability Rights Commission looks at independent living and human rights.
- then we will look at how we are working together to tell people about these rights.

Independent living, disability and human rights

The DRC thinks there should be a right to independent living for all disabled people. This means that all disabled people
should have the **same choice, control and freedom as everyone else** – at home, at work and in the community.

The Human Rights Act makes all public bodies - like NHS Trusts and local councils – pay attention to the **European Convention in Human Rights** (ECHR). This allows people whose rights have been ignored to take organisations to court.

The Human Rights Act promotes **respect for human rights**. Public bodies can use the Act can help to them work better. The Audit Commission says this should mean that decisions about services respect people’s rights, such as:
- the right to **privacy and family life**
- the right to a **fair hearing** (for example, in court)
- the right **not to suffer bad treatment**.

Managers will know what they need to do under the Act. When they make decisions, they will balance an **individual’s** rights against those of the **community**.

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The ideas of ‘independent living’ and those of the ‘Human Rights Act’ are quite similar.

**Human rights** are based on four values:

- **Dignity**
- **Autonomy**
- **Equality**
- **Solidarity**

**Dignity:** by **first** looking at the real value of a person being, and only then their
of a person being, and only then their disability, human rights put the person at the centre of all decisions about them.

The problem of disability is that society doesn’t look at the difference of disability. The State must get rid of barriers. It must respect the dignity and equal rights of all persons.

**Autonomy:** People can make their own free choices. Human rights protect those who cannot make their own choices. It also supports those people who can make their own choices.

**Equality:** Every person has inherent worth. They are equal - whatever their difference.

So for disability this means:

- Stopping people being excluded (like in transport and getting in to buildings)
- supporting people to take up jobs, education and other roles
- stopping discrimination (through laws) and setting up a programme to look at how people think about disability.

**Solidarity:** This is to support people to take part in everyday activities in society.

**Independent Living** challenges the barriers that stop people taking part (‘Dignity’). Where people can make decisions for themselves, it also challenges the failure to support them to
challenges the failure to support them to act on their choices. (Autonomy).

Independent Living also means disabled people having the same opportunities as non-disabled people (Equality) and that disabled people can take part in society (Solidarity).

We can look at Independent Living, human rights and social care in different ways:

Without independent living disabled people cannot use all their human rights: For example, disabled people living in care homes may not be able to be in touch with family and friends as much as they want.

Independent Living gives people the power to use their human rights: Making sure disabled people can live ordinary lives lets them use their rights. Independent living is a way of people using these rights. Providing social care helps support people to live ordinary lives.

Not respecting human rights harms Independent Living. For example, giving breakfast to residents while they are sitting on their commodes (toilet chairs) is very bad for their independence, dignity and
autonomy.

A right to Independent Living is needed: While disabled people are entitled to the same human rights as non-disabled people they cannot really benefit from such rights, unless extra needs are met:

These might be mobility needs (like a walking frame or wheelchair) or help with communicating or personal assistance. Disabled people need to have the right to these extra needs.

How well are human rights being met today?

There are five problems with way social care works today:

- It places duties on local authorities to offer services. It does not give rights to individuals to get support
- There is no right to live at home rather than to live in institutional care (like group homes or wards)
- It does not cover support to take part in leisure activities, work, have relationships, or look after family members
- There is no right to advocacy
- Protecting the rights people have means using the law and courts. This
can be difficult and there is not enough support for people to use them.

Spending money on independent living
People often think about disabled people only as users of support services. This is wrong and unfair.

Disabled people are customers, workers, students, parents, taxpayers and voters, and community members. Support services should help people fight against barriers and to take part in all of these ways.

This is why spending money on independent living needs to be seen as money well spent. Playing a bigger part in society helps disabled people - but it also helps governments, businesses and communities.

It is wrong for a disabled person to be made to live in an institution (like a group home or ward) to save money. Since independent living helps disabled people benefit the rest of society too, it makes the argument for all disabled people to live independently very strong.

Winning the right to independent living
Disabled people have a difficult time because they have no right to independent living. Many people are
stuck in residential care or afraid of being forced into residential care, because of rules about spending money in their area.

For example:

- a woman in her twenties cannot get out of residential care because her care costs more than the care home.

- A woman more than 100 years old cannot stay in her own home because her care there cost more than her living in a care home.

- Deaf people have such poor access to communication support that it affects their health care, their social lives, their education, even going shopping.

- Some people with learning difficulties and who are said to have challenging behaviour may be sent to a private institution. Here they may be cut off from the outside world.

These people cannot use their human rights. They cannot take part in daily life. If they had independent living support, and advocacy, they could change their situation.

The future of independent living

So, with the Disability Rights Commission and others groups, The National Centre for Independent
Living is looking for a system that:

- support **community living**, not care in institutions
- offers support which helps people take part in society
- makes sure social care offers **choice and control**
- looks at the **barriers** to people taking part in society

We want a future in which disabled people:

- have the right to make **real choices** about how their support needs are met and are involved in the planning and design of support services;
- can use support services that are based on **choice, control, autonomy and taking part**;
- are **treated fairly** when using services.

Also, all disabled people should have access to **advocacy**. Advocacy, information and advice networks need to have enough money to meet people’s needs.

All disabled people should be able to live in homes in which they can move around, carry out their lives and live privately and safely.

**All disabled people should have a right to support to meet their access, information and communication**
needs.
Organisations who pay for or offer services need to know that social inclusion depends on disabled people having communication support, aids and equipment (like hearing aids, computers and controllers).

Information about services and support to use this information is very important for independent living.

Some of these aims can be met soon; others will take planning and spending money. To make all this happen, we need to start planning now, so the future comes a bit closer.

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November 2004
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