

Inclusion Scotland

Making the most of your

Human Rights to Independent Living

A tool-kit
for disabled people
and
their advocates

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Introduction

All human beings have human rights. They are very important because they include things like the right to liberty and the right not to be tortured or treated in a degrading or inhuman way. But not everyone knows what their human rights are or how to make use of them.

Disabled people's human rights are not always respected. They can be denied their human rights by discrimination, poorly designed services, buildings and transport and poorly trained service-providers. Sometimes disabled people have very bad experiences. For example, they may have food placed out of reach or be left on a toilet for hours. They may have their right to privacy or to spend time with their family ignored. If they are a mental health service user and become unwell, they may be restrained in a painful manner or not consulted about their treatment. This means their human rights are being abused.

Disabled people do not have to put up with such treatment. You can use human rights to challenge bad practice and promote independent living, so that disabled people can have choice and control over their own lives, just like anyone else. If you use your human rights like this it could make a huge difference, not just to your life but to the lives of all disabled people.

The tool-kit

The purpose of this tool-kit is to provide the information that disabled people need to realise their human right to live independently. It is for disabled people and their advocates.

People are sometimes put off using human rights because they think it would be very difficult. It is true that rights laws can be complicated and sometimes everyone needs to get specialist advice.

But this tool-kit tries to explain human rights in ways which make them easier to understand. It gives you practical ideas about how you can use them to promote independent living. It also tells you where you can go to find more information.

Where the tool-kit came from

This tool-kit was the result of a project funded by Inclusion Scotland. They wanted to reach across Scotland to inspire disabled people to use Human Rights to promote independent living and to strengthen the Disabled People's Independent Living Movement.

The project involved training three organisations on human rights and how to use them to promote independent living. The organisations were:

- Glasgow Disability Alliance (GDA). This organisation is a membership-led organisation of disabled people and groups in Glasgow. Its mission is to act as a collective, representative voice of disabled people, promoting equality, rights and social justice.
- Angus Independent Advocacy (AIA). This organisation provides accessible independent advocacy for adults who may have a mental health problem, a learning disability, dementia, an acquired brain injury, or who have frailty in old age. They aim to ensure that their rights and interests are fully represented.
- Inverclyde Council on Disability (ICoD). This organisation provides advice, information, advocacy; consultancy, a quarterly newsletter and a Shopmobility Service along with other new and developing services. They provide these to disabled people, their carers, families, the general public, statutory and non-statutory agencies, the private sector and any other interested parties.

This tool-kit was developed with their feedback and ideas. The aim was to co-produce the tool-kit as much as possible because, as they are organisations of disabled people and advocates, they know best what is likely to be useful for other disabled people and advocates.

Where to start

Before exploring how human rights can promote independent living for disabled people we need to define what 'independent living' means, what 'disability' means and what 'rights' mean.

Defining independent living

The Independent Living in Scotland project defines independent living as:

“Independent living means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.”

So independent living means having choice and control over how you live your life, just like anyone else. It doesn't mean doing everything for yourself. It doesn't mean living alone. You might live alone but you might live with other people or even in a care home. It is still possible to have what you need for independent living.

Disabled people and their organisations have drawn up a list of the rights that disabled people need for independent living. There are 14 of them.

Right 1: A decent income including state benefits for those unable to work.

Right 2: Accessible and adapted housing is required with the need for houses to meet agreed standards.

Right 3: Personal Assistance should be provided through direct payments or self-directed support to enable choice, control and flexibility.

Right 4: Accessible information- this should be readily available in accessible formats including easy read and plain language.

Right 5: Communication support – this should be readily available so that people can participate in all aspects of life.

Right 6: Advocacy and working towards self-advocacy- funding should be provided for organisations led by disabled people to provide advocacy and support the development of self-advocacy through confidence building, peer support and other learning.

Right 7: Technical aids, equipment & technology are important in reducing barriers and promoting a better life for disabled people.

Right 8: Inclusive education including lifelong learning is a critical right for disabled people with so much of life being determined by access to education and the opportunities this brings.

Right 9: Equal opportunities for meaningful employment and training for work.

Right 10: Accessible and inclusive healthcare for physical, emotional and mental health for all disabled people.

Right 11: Peer support including organisations led by disabled people should be recognised as important.

Right 12: Meaningful opportunities for civic and political participation, citizenship & involvement in decisions which affect our lives.

Right 13: Full access to our environment should be available for everyone including access to buildings, transport, parking, public spaces, streets, pavements, workplaces as well as shopping areas.

Right 14: Fully accessible & affordable transport: should be demand-led and allow for spontaneity and flexible travel and should also apply to all modes of travel.

Glasgow Disability Alliance have worked out that disabled people have rights to all these things on paper. Some of them are human rights and some are other types of rights. However, just because disabled people have rights on paper it doesn't mean they have all these things. They might have to take action to turn their rights into reality.

Defining disability

There are lots of models of disability. Each model is a way of understanding disability. Each model has different implications for how disabled people are treated. It is therefore very important which model you use. Here are some of the most common models.

Medical model: this model says that disability is caused by impairment. The person or their impairment is the problem and the solution is to 'adjust' (cure, treat) the person/ their impairment. The medical profession and other professionals have the power while disabled people are passive recipients.

Social model: this model says that disability is caused by the barriers which arise because society fails to take account of people who have impairments. The ways in which society operates is the problem and the solution is to 'adjust' society by removing barriers. If social barriers are removed then, even if a person has an impairment, they don't experience disability. Disabled people are empowered and others have to make changes to remove social barriers.

Social barriers include negative attitudes, inaccessible environments (buildings and outdoor spaces), how things are organized (like not allowing enough time), how things are communicated, inaccessible transport and cost. All these can stop disabled people participating as equal citizens.

Charity model: this model says disabled people can't do things for themselves and the solution is for them to depend on charity. Charities or non-disabled helpers have the power in this model, not disabled people.

Personal tragedy model: this model sees disability as a personal tragedy. Disabled people are tragic victims or heroic survivors – or both! This model often goes with the charity model.

It's clear that not all these models fit well with independent living if that means disabled people have freedom, choice, dignity and control. Doctors have control in the medical model and charities or non-disabled helpers have control in the charity model. Disabled people have no choice in either model. The personal tragedy model treats disabled people as objects of pity and this does not respect disabled people's dignity. Only the social model fits with independent living.

Defining rights

To have a right to something means that no one can stop you from having it and others have to take action so that you can have it.

“When something is defined as a right, it means that someone holds a claim, or legal entitlement, and someone else holds a corresponding duty or legal obligation. With a rights-based approach, effective action moves from the optional realm of charity into the mandatory realm of law, with identifiable rights, obligations, claims holders and duty holders.” (Northern Ireland Human Rights Commission resource: ‘Inspiring Practice’)

Unfortunately rights aren’t always simple to understand. Here are some ways in which rights can differ:

- **Rights just to access a service:** For example, you may have a right to health-care but you don’t have a right to a particular treatment. Similarly, if you are a child you have a right to education (in fact you don’t have a choice!), but not to go to a particular school.
- **Rights only for some people and rights for everyone:** Welfare benefits are a good example of rights you can only get if you fulfil certain criteria. For example, to get a means tested benefit you must have income and savings below a certain level. How much you get may also depend on things like whether anyone in your household has a disability. Of course, you have to prove you fulfil the criteria and the people assessing you may disagree. Rights for everyone are called universal rights. Child benefit is a universal benefit because anyone who has responsibility for a child can get it. It does not matter how much income or savings they have.
- **Rights and responsibilities:** Some rights are conditional, which means you can only have them if you do certain things. For example, you can only get jobseekers allowance if you can show that you have been actively seeking work.
- **Rights to challenge decisions:** If you don’t agree with a decision made by an assessor usually you will have rights to challenge it. Processes differ depending on what sort of right it is. For example, to challenge a decision that you’re not entitled to a benefit you have

rights to have that decision reviewed and then you can appeal. If you don't get the community care services you need you can complain and if you are not satisfied with the outcome you can take your case to the Scottish Public Services Ombudsman. Sometimes you might take a case through the court system or to a tribunal.

If you look back at the section on models of disability you can see that not all the models fit well with a rights-based approach. In both the medical model and the charity model what disabled people get depends on the judgement of other people. Again, only the social model fits with a rights-based approach. Disabled people need rights to enforce action to remove social barriers.

Remember the ways in which rights can differ when you look at the next section which is about human rights.

Your rights

What are human rights?

Human rights are based on principles of fairness, equality, dignity and respect – just what independent living is all about. They are basic, fundamental rights. They aren't luxuries and they aren't a wish list. They concern what it is to be human. Everyone has human rights, which means they are universal rights. They cannot be taken away or given away (the word for this type of right is 'inalienable'). You don't have to prove you are 'deserving' rather than 'undeserving'. You don't have to balance rights with responsibilities in order to get human rights. But if you don't respect other people's human rights, sometimes some of your rights can be restricted.

Action to recognise human rights was started by international organisations in Europe and the United Nations. Human rights take different forms. Sometimes they are contained in legislation and sometimes in Conventions. How they work, what you can do with them and how you make challenges using them differs depending on the form they come in. We will explain more about this in this section.

We will also explain how different types of human rights relate to each other and to other sorts of rights. We will talk mostly about the Human Rights Act 1998 and the United Nations Convention on the Rights of Disabled People.

The Human Rights Act 1998 (HRA)

The HRA was passed in 1998 but it only became law on 2 October 2000. The rights in the HRA were first set out in something called the European Convention on Human Rights. The HRA brings those rights into UK law and this gives people the power to take legal cases through UK courts. Before the HRA, people who thought that their human rights had been violated had to take their case to the European Court of Human Rights. Even now, if your case is rejected in the UK courts, you can still appeal to the European Court of Human Rights

The HRA only covers 'public bodies' like government departments, courts, hospitals, schools, local councils. It doesn't cover private individuals or companies or voluntary sector organisations. However, where private or voluntary sector bodies are **performing a 'public function'** the HRA can apply. A public function means they are delivering a service on behalf of a local authority or doing something else which concerns a 'public body obligation' such as protecting individuals against threats to their life or interferences with their liberty carried out by private persons.

The rights in the HRA are not all equally powerful. A few of them are 'absolute'. This means that they apply to everyone in all situations and cannot be restricted. The rights not to be tortured or enslaved or treated in an inhuman or degrading way are absolute rights.

However, most rights in the HRA are 'limited' or 'qualified'. This means that although everyone has these rights equally, they can be restricted in some situations. A limited right can only be restricted in specified situations. A qualified right can be restricted when it is necessary to protect the rights of others. For example, if someone is using their right to freedom of expression to encourage racial hatred, that right can be restricted to ensure the safety of others and because it's a qualified right. The question is whether restricting a qualified right is 'reasonable' and 'proportionate'.

In relation to qualified human rights, public authorities can take resources into account but they can't base their decision not to respect a qualified right just on a lack of resources.

Rights protected by the Human Rights Act

The Human Rights Act turns into UK law the following rights contained in the European Convention on Human Rights: Each one is called an article. There are also things called 'Protocols' which have been added since the Convention was first written. Some protocols are about procedure but others add new rights.

This list is just a summary of the main articles. Absolute rights are in bold.

As you read through them, think about how they might relate to disabled people's experiences and independent living.

Article 2: The right to have your life protected by law [but this must not place a disproportionate burden on public authorities to protect or prolong life in all circumstances].

Article 3: The absolute right not to be tortured or treated in an inhuman or degrading way.

Article 4: The absolute right to be free from slavery or forced labour

Article 5: The right to liberty [limited – does not apply where someone is suspected or convicted of a crime and imprisoned, or detained under mental health law].

Article 6: The right to a fair trial.

Article 7: The right to no punishment without law.

Article 8: The right to respect for private and family life, home and correspondence.

Article 9: The right to freedom of thought, conscience and religion.

Article 10: The right to freedom of expression.

Article 11: The right to freedom of assembly and association.

Article 12: The right to marry and found a family.

Article 14: The right not to be discriminated against in relation to any of their rights unless it can be justified objectively.

Article 1 of Protocol 1: The right to peaceful enjoyment of possessions.

Article 2 of Protocol 1: The right to education.

Article 3 of Protocol 1: The right to free elections.

In addition the Act abolishes the death penalty (Article 1 of Protocol 13)

You can find a more detailed description of each of these rights, with examples, at: <http://www.equalityhumanrights.com/human-rights/what-are-human-rights/the-human-rights-act/>

You can see the full wording of the articles at:
http://www.direct.gov.uk/en/governmentcitizensandrights/yourrightsandresponsibilities/dg_4002951

The United Nations Convention on the Rights of Disabled People (UNCRDP)

The actual title is the 'United Nations Convention on the Rights of Persons with Disabilities'. In the UK 'persons with disabilities' is regarded as language which reflects the medical model of disability. This is because it attaches the disability to the person rather than recognising that it is society that disables people who have impairments. We will instead refer to the Convention as the UN Convention on the Rights of Disabled People, in keeping with the social model of disability.

The purpose of the Convention is "To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all

persons with disabilities, and to promote respect for their inherent dignity” (Article 1)

The UNC doesn't give disabled people new rights. You might therefore wonder why disabled people campaigned long and hard for it. The Convention is important because it:

- Places responsibilities on governments not only to respect the human rights of disabled people but also to act to promote those rights
- Makes governments accountable because they have to report to the UN Disability Committee on what they've done. This Committee is made up of 12 independent experts
- Says disabled people should be involved in implementing the Convention and monitoring progress

Although you can't take a legal case on the basis of an article in the UNC it can be a very useful tool in pushing for change because it:

- Can be used to challenge, clarify, interpret and strengthen existing legislation or policy. In particular, it helps to interpret and explain what the articles in the Human Rights Act mean for disabled people, so it can be used to support a legal challenge using the HRA
- Provides a framework for negotiations
- Can be a useful tool for changing attitudes among service providers, policy makers and the general public
- Could lead to better and more responsive services
- Can increase the confidence of disabled people to challenge unfair or discriminatory practices.

The UK Government signed the UNCRDP in 2007. This meant that they agreed with what it said. They then 'ratified' the Convention in 2009 which means they promised to do what the Convention says and act to protect disabled people's rights. If the Government fails to ensure that public

authorities are implementing the Convention then both the Government and those public authorities may be in breach of the Convention.

The Convention is made up of different articles which lay down the underlying principles, state what disabled people's rights are and explain the obligations of governments and other public bodies to disabled people. There is also something called an 'Optional Protocol'. This means that individuals can bring petitions to the UN Disability Committee, as a last resort. The Committee has the authority to undertake inquiries into grave or systematic violations of the Convention. But do get advice before you go down this road. You could ask the Equality and Human Rights Commission or the Scottish Human Rights Commission.

Here is a summary of what's in the UNC.

Guiding Principles under UNCRDP

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of person
- b. Non-discrimination
- c. Full and effective participation and inclusion in society
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e. Equality of opportunity
- f. Accessibility
- g. Equality between men and women
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Rights under the UNCRDP

Article 5 Equality and non-discrimination

Article 6 Women with disabilities

Article 7 Children with disabilities

Article 8 Awareness-raising

Article 9 Accessibility

Article 10 Right to life

Article 11 Situations of risk and humanitarian emergencies

Article 12 Equal recognition before the law

Article 13 Access to justice

Article 14 Liberty and security of person

Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 16 Freedom from exploitation, violence and abuse

Article 17 Protecting the integrity of the person

Article 18 Liberty of movement and nationality

Article 19 Living independently and being included in the community

Article 20 Personal mobility

Article 21 Freedom of expression and opinion, and access to information

Article 22 Respect for privacy

Article 23 Respect for home and the family

Article 24 Education

Article 25 Health

Article 26 Habilitation [this is about learning new skills] and rehabilitation

Article 27 Work and employment

Article 28 Adequate standard of living and social protection

Article 29 Participation in political and public life

Article 30 Participation in cultural life, recreation, leisure and sport

You can find a more detailed explanation of the UNCRDP at:

<http://www.equalityhumanrights.com/human-rights/a-guide-to-the-un-disability-convention/>

For the full text of the Convention, a plain English and an Easyread version see: <http://www.un.org/disabilities/>

Reservations and an Interpretive Declaration

The UK government has said it will not implement the UNCRPD in full. It has made 4 reservations. This means there are 4 areas where the Government will not be taking action. It has also made one 'interpretive declaration'. This sets out the Government's understanding of what an article means. These restrictions could be removed, if the Government wanted to remove them.

Article 12: Equal recognition before the law: The reservation relates to the fact that the Secretary of State may appoint a person to exercise rights in relation to social security claims and payments on behalf of someone who is for the time being unable to act. There is no system in place yet for a regular review of whether appointees should continue in that role. The UK government has acknowledged the need for a "proportionate system of review" and is "working towards it". Disability activists have asked the government to remove this reservation and provide a definite time-scale for replacing the current system.

Article 18: Liberty of movement and nationality: The UK government will continue to apply immigration rules as it sees fit. The Equality and Human Rights Commission (EHRC) believes this reservation is incompatible with Article 46 of the Convention. Article 46 states that “Reservations incompatible with the object and purpose of the present Convention shall not be permitted”

Article 24: Right to education: Disabled children can carry on being educated outside their local community. It has also made an **interpretive declaration** that: ‘general education’ includes special schools as well as mainstream schools. The Scottish Government has also limited its duty to provide education in a mainstream school by making it dependent on the child’s ability/aptitude, whether including them would make education less efficient for other children and what it would cost. The Equality and Human Rights Commission opposes these limits on Article 24 because it thinks they are unnecessary and not compatible with the Convention’s firm commitment to inclusion.

Article 27: Right to Work: The UK Government has always exempted the armed forces from laws which mean they would have to employ disabled people on the grounds that forces always need to be ready to go into combat. Rights organisations have criticised this reservation.

How rights fit together

The HRA and the UNCRDP

As you can see, there is not a direct link between the rights in the Human Rights Act and those in the UNCRDP. But it is helpful to think through how they fit together. You can see:

- where the HRA supports and strengthens rights in the UNCRDP
- how the UNCRDP can be used to explain what rights in the HRA mean for disabled people.

Other rights

Human rights don't exist all alone. There are other sorts of rights which disabled people can use with human rights to promote independent living. There are also laws which interact with qualified human rights. These can explain what would be considered 'proportionate'. They might set out reasons why a qualified human right could be restricted.

The table on the next page sums up how human rights developed and how they interact with other laws. It just covers the main ones – it isn't a complete list. New laws may be made which will need to be added.

Human rights, other rights and laws

Date:		Notes:
1948	UN Declaration of Human Rights	One of the first actions of the newly established United Nations after the Second World War was to adopt the Universal Declaration of Human Rights (UDHR). This was the first internationally agreed statement on human rights. It lays down the rights which everyone is entitled to by virtue of being human, providing a foundation for human rights conventions and law.
1951 Came into force in 1953	European Convention on Human Rights	This was drafted by all states in the Council of Europe, including the UK but didn't become part of UK law until the Human Rights Act 1998. Cases had to be taken to The European Court of Human Rights in Strasbourg which was expensive and time-consuming. The Court found against the UK government on many occasions. Although not bound to do so, some UK laws were changed as a result.
1968	Social Work (Scotland) Act	This Act placed a duty on local authorities to 'promote social welfare'. It continues to underpin the work of all social work services and is the basis for later social work legislation e.g. The Regulation of Care (Scotland) Act 2001. Human rights instruments can be used to interpret the meaning of 'social welfare' and strengthen disabled people's case for increased/improved provision.
1995	The Disability Discrimination Act	This made it unlawful to discriminate against disabled people in connection with employment, the provision of goods, facilities and services. Employers, educational establishments and service providers must make reasonable adjustments to ensure disabled people can access their services and fully participate. Human rights

		instruments can help to interpret some concepts, for example what is meant by 'reasonable adjustment'.
1998 (implemented 2000)	The Human Rights Act	The rights contained in the European Convention became part of UK law. This means that if you take a case it goes through our court system. If the UK courts reject your case you can still appeal to the European Court.
1998	The Scotland Act	This established the Scottish Parliament and Government. All Acts of the Scottish Parliament must comply with the European Convention on Human Rights (ECHR) and human rights must be respected/realised at all levels of government.
2000	Adults with Incapacity (Scotland) Act	This is intended to protect the welfare of adults unable to look after themselves because of a mental disorder or inability to communicate and in the event of others making decisions on their behalf regarding e.g. financial decisions, property and medical treatment.
(implemented 2005)	Mental Health (Care and Treatment) Scotland Act	This reformed Mental Health legislation to reflect changes to more community-based services; the greater involvement of service users and their carers in decision making and greater awareness of the need to respect human rights.
2005	Disability Discrimination Act	This closed gaps and loopholes in the 1995 Act and introduced the Disability Equality Duty.
2006	United Nations Convention on the Rights of Persons with Disabilities	The UNCRPD doesn't give disabled people any new rights. It brings together existing rights and spells out what they all mean for disabled people's human rights. You cannot use the UNCRPD to take a legal case but you can use the Acts that underpin it. The Government must report regularly on what it has done to implement the UNCRPD.

2007	Adult Support and Protection (Scotland) Act	This makes new provisions for the protection of adults who are: unable to safeguard their own well-being, property, rights or other interests; at risk of harm; and because they are affected by disability are more vulnerable to being harmed (harm includes neglect). Any intervention must provide benefit to the adult which could not have been reasonably achieved without intervention and the new public sector Equality Duty means that public authorities must have due regard to the intervention must be the least restrictive option to the adult's freedom.
	Equality Act 2010 Includes Public Sector Equality Duty which comes into force April 2011	This brings together nine separate pieces of legislation to simplify and strengthen protection against discrimination. Employers, education providers and service providers in UK must make 'reasonable adjustments' to ensure disabled access; need to eliminate unlawful discrimination, harassment and victimisation; advance equality of opportunity between different groups; foster good relations between different groups. The UNCRPD can be used to interpret some concepts e.g. what is meant by 'reasonable adjustments'.
2011	Patient Rights Scotland Act	Amongst other things this reconciles patients' rights law in relation to personal privacy and current non-compliant complaints procedures with human rights law.

Rights to independent living

This section talks about human rights which are likely to be particularly important for independent living.

There is one article in the Human Rights Act which is nearly always relevant to independent living and that is article 8: “the right to respect for your private and family life, your home and your correspondence...”. There is also one in the UNCRDP which is specifically about independent living and that is article 19: “the equal right of all persons with disabilities to live and have full inclusion and participation in the community”. However, independent living covers a lot of different things. It includes housing, transport, employment, income, education, and health. It is no surprise that different human rights will be relevant in different situations, often in addition to article 8 (HRA) and article 19 (UNCRDP). It is important to look closely at all the rights every time to see which might apply.

Have a look back at the rights to independent living listed in the section on defining independent living (in the introduction). Can you see how human rights underpin them?

Human Rights Act

In addition to article 8, there are a few other articles which may be particularly important for independent living.

- Article 3 gives people an absolute right not to be tortured, or to have to suffer inhuman or degrading treatment. It makes no difference whether inhuman or degrading treatment was done on purpose. This might cover neglect, severe bullying and harassment, being washed or dressed without regard to your dignity, being restrained with excessive force or having to endure unsanitary or poor conditions.
- Article 5 gives people the right to liberty, which might be relevant in situations where people are detained or to locked doors in care homes.
- Article 14 which is the right not to be discriminated against. This only applies to the ways in which other articles are implemented, not just by

itself. So, if your human rights are being implemented less favourably because you are a disabled person, or because of your age, sex, race or other such characteristics, this article might be relevant.

UNCRDP

Although you should look closely at all the rights every time to see if they apply, it is possible to group them together into subject areas. The lists below are just intended to be a helpful start. In any one case some articles may be more relevant than others. There may also be problems which you feel do not fall under any of these headings. Let us know what they are so we can update this tool-kit or try and make up your own list of relevant articles under new headings.

Housing

- Article 9 – Accessibility
- Article 19 - Living Independently and Being Included in the Community
- Article 20 – Personal mobility
- Article 23 – Respect for Home and Family
- Article 27 – Work and Employment
- Article 28 – Adequate Standard of Living and Social Protection

Advocacy

- Articles 9 – Accessibility
- Article 19 - Living Independently and Being Included in the Community
- Article 21 – Freedom of expression and opinion, and access to information
- Article 29 – Participation in political and public life
- Article 30 – Participation in cultural life, recreation, leisure and sport

Inclusive communication

- Article 9 - Accessibility
- Article 19 - Living Independently and Being Included in the Community
- Article 21 – Freedom of expression and opinion, and access to information
- Article 27 – Work and employment
- Article 29 – Participation in political and public life
- Article 30 – Participation in cultural life, recreation, leisure and sport

Transport

- Article 9 - Accessibility
- Article 19 - Living Independently and Being included in the Community
- Article 20 - Personal Mobility
- Article 30 - Participation in cultural life, recreation, leisure and sport

Difficult Cases

What we've tried to do in this section is give you some basic information about human rights. This has been simplified to make it easier to understand. In many cases this should be enough to help you to identify relevant human rights and plan action. But there will be occasions when things are not straightforward.

Here are two examples:

- where there seems to be a conflict between a person's right to privacy and concerns that their right to life may be compromised if they are not properly supervised e.g. they might be suicidal
- where there seems to be a conflict between a person's right to family life and the rights of a child to be protected from harm

There are no easy answers to some of these issues but this should not put you off. On the contrary, disputes can sometimes be more easily resolved by looking for solutions based on respect for a person's human rights. The following real-life case studies illustrate how this can work:

- A woman was an inpatient at a mental health hospital in London. She became very distressed after being told she could not close the door to her room because she was under 24 hour observation. She felt this was an invasion of her privacy (Article 8 of The Human Rights Act)

In addition to its ordinary duty of care towards her, the hospital had a positive obligation to protect her right to life (Article 2) because she had a history of self-harm including attempted suicide. This was why her privacy had been restricted. However, any interference with her privacy needed to be proportionate to the risk of her harming herself.

Supported by her advocate, the woman arranged a meeting to discuss these issues with her treatment team. During the meeting, the woman told the treatment team that being under 24 hour observation caused her great anguish. She asked the treatment team to explain why she was under observation, and how long it might be expected to endure. This they did.

An agreement was reached that from then on the woman would be able to close the door when using the bathroom, provided she was searched first, the door was unlocked, and the nurse remained outside.

Being given the chance to express her feelings and to discuss and then agree changes to the observation process gave much needed comfort to the woman. Afterwards she told her advocate that she could now see that the observation process was not a form of punishment, as she'd thought, but was instead designed to protect her human rights.

Source: Cambridge House Mental Health In-Patient Advocacy Project, quoted on the British Institute of Human Rights Site at http://www.bihar.org.uk/sites/default/files/BIHR%20Changing%20Lives%20FINAL_0.pdf

- A learning disabled couple with children was subjected to unannounced visits on a daily basis by their children's social workers who were concerned about the couple's ability to raise their children.

The unpredictability of the visits caused immense distress for the parents who felt extremely anxious, and became afraid to answer the door. With the help of their advocate, the couple argued that the visits were a breach of their right to respect for private and family life. The local authority considered this argument and agreed that from then on visits would occur at a time pre-arranged with the family. This helped the parents to regain some control over their lives and to feel their privacy had been restored.

Source: The Human Rights Act: Changing Lives, Second Edition at http://www.bihar.org.uk/sites/default/files/BIHR%20Changing%20Lives%20FINAL_0.pdf

Taking action

A Human Rights-Based Approach

To promote rights to independent living, the broad aim is to get organisations to take a human rights-based approach to the way they design and deliver goods

and services. But what exactly do we mean by a human rights-based approach? Here is how some people have described it:

“A human rights-based approach is a way of organising policy choices and practice on a day-to-day level to ensure that human rights are at the centre of how organisations work as well as how they measure success. It emphasises the importance of the empowerment and participation of people affected by decisions to claim their rights, and the accountability of those responsible for human rights.”

(Scottish Human Rights Commission)

“The human rights approach starts from the principle of human autonomy”
(Mental Welfare Commission for Scotland)

Developing your case

Before you take action you first need to think about the case you are going to make. The following method has been adapted from the original version which can be found at the Scottish Human Rights Commission website at

<http://www.scottishhumanrights.com/careaboutrights/flowchart>

It is called F.A.I.R for short. F.A.I.R. stands for Facts, Analysis, Identification and Review.

Facts What are the important facts to understand? What is the experience of the individual? Is the individual being heard and if not, do they require support to do so?

Analysis Which human rights apply? Are they in the Human Rights Act or the Convention? Remember there may be more than one. If any of them are absolute rights in the Human Rights Act, like the right not to be treated in an inhuman or degrading way (Article 3) then they cannot be restricted in any way. If it isn't an absolute right, is the justification for restricting the right 'proportionate'? You may also want to think about whether any other types of rights are relevant.

Identification What changes are necessary? Who has responsibilities for causing the problem and/ or helping to make positive changes?

Review Have actions taken so far been recorded? You should also review how the individual affected has been involved in making the case to ensure that it is being driven by what they want to happen.

Case Study Example

- Michael spent most of his life working in the mines in Lanarkshire. Well into his 80s he is now in a care home on the edge of the mining village where he was brought up. As a result Michael is well known not just to the others in the home but by many of the staff whose parents and grandparents he knew. Michael is in poor health and as a result of his work suffers from emphysema and is breathless.

Michael has a daughter, Lisa, who moved away from home when she was 18, qualified to be a nurse but has now returned back to the village after her retirement. She is a strong character and frequently takes over the tasks of the care staff and constantly inspects their work and support.

One day Michael asks to be supported to go to the toilet which the duty staff begin to respond to. Lisa insists that she will take her dad to the toilet. Michael begins to get upset and starts to breathe more heavily and to get agitated. The staff ask Lisa to leave but she refuses saying that as a professional nurse and as a daughter she has the right to stay and make sure that they are looking after her father properly.

Source: <http://www.scottishhumanrights.com/careaboutrights/flowchart-casestudy>

F is for Fact: Michael has emphysema and is breathless. He does not appear to want his daughter Lisa to be present when he is being supported to go to the bathroom.

A is for Analysis: Michael's right to privacy under Article 8 is at stake here. This right can be restricted if the restriction would be 'proportionate'. The justification for the restriction is that Lisa wants to be involved in her father's care. This does not appear to be proportionate as it does not take Michael's wishes into account and is not necessary for his care.

I is for Identification: The care workers have a responsibility to explain to Lisa that it is her father's wishes and that he has a right to have privacy for his personal care needs. Lisa has a responsibility to take account of her father's right to privacy.

R is for Review: Has Michael participated in decisions made about his care? Have Michael's rights been explained to Lisa? Are staff aware of the privacy rights of Michael? Have the actions taken and Michael's preferences been recorded?

Things you can do

Once you have thought through your case you need to decide what action to take.

a) The Human Rights Act

Even if you have legal rights under the HRA, it's worth remembering that taking legal action can be very time-consuming and it can cost a lot. Before you do that there are lots of other actions you take using human rights.

Educate: Talk to whoever is not respecting your human rights. Explain about human rights and what they need to do to respect them. Give them the benefit of the doubt. Perhaps they don't realise what they're doing, how badly it's affecting you or what they could do to make it better.

Complain: If that doesn't work, make a formal complaint. All public bodies should have a complaints procedure.

Advocacy: You might get advocacy support to help you make your case.

Campaign: Particularly if the problem is affecting a lot of people you could work with disabled people's organisations to campaign for change. There is more about this in the next section.

If all else fails:

Specialist legal advice: You need to know how strong your case is before you launch into the legal system

UK courts: You can take your case through the UK court system. This might include the sheriff court, an employment tribunal and eventually the High Court of Justiciary for criminal cases and the Supreme Court for civil cases.

European Court of Human Rights: Only when you've gone through the UK courts can you apply to the European Court of Human Rights to hear your case.

b) The UNCRDP

Using the UNCRDP you could also:

Optional Protocol: Investigate how you might use this (see information on the Convention). You'll probably need to get some specialist advice.

Contribute to monitoring of the UNCRDP: The Equality and Human Rights Commission and the Scottish Human Rights Commission collect evidence about how well the UK Government is implementing the Convention. You could get in touch with them and tell them about your experience.

The UK Disabled People's Council recently set up 'Rights Watch UK' to collect evidence of whether the Government is complying with the UN Convention on the Rights of Disabled People. See www.disabilityrightswatchuk.org.

Pushing for change

The change you want to see may relate to the treatment of one individual. In that situation, for example, it may be a matter of challenging the decision on the person's care package, or the behaviour of a particular support worker. It may just relate to an incident that occurred once, or it may concern a problem that the individual has experienced repeatedly.

Pushing for a change that will benefit one person is obviously worth doing. This is where advocates often play an important role. But it may be that it isn't just one person – maybe you yourself - who is experiencing the problem. If you can get something changed that will benefit lots of people, that's even better. You may not know if other people are also experiencing the same problem but the chances are that disabled people's organisations will know, because they are in touch with lots of disabled people. It might then be possible to join together to campaign for change.

This section explores what organisations need to do to campaign successfully for policy change. It also gives you some ideas about what you could do. The

next looks at what you or your advocate might do to change things for you/ an individual. Both build on F.A.I.R..

Campaigning for policy change

Define your campaign objective: When you have got all the **facts** about what the problem is, the next thing to do is to decide exactly what it is that needs to be changed and what you want the outcome to be. It is always good to say what you do want and not just what you don't want. The more specific you can be the better. If you are too vague it is hard to know what action to take, who to target or how to measure success.

Build your case: Use the previous section on your rights to help you do an **analysis** of which rights are relevant. This is the starting point for building your case.

But there is more you can do to strengthen it. For example, you can:

- see if there is research evidence about the problem and about what would solve it
- commission research – there may be academics who specialise in the issue
- do some research yourself, for example an organisation could carry out a survey of your members to get their views and experiences
- start a petition to show that lots of people agree with you
- ask a friendly MSP or MP (depending on whether the issue is a devolved or reserved responsibility) to ask a Parliamentary Question about trends or numbers affected by the problem.
- find examples of good practice which demonstrate that what you want to happen works.

All of these are ways to make your case more convincing. Can you think of any other ways to strengthen your case?

Working out who to target: The next stage is **identification** of who has the power to make the change and who else has a role to play. Be very clear what you are asking them to do – and make sure it is something they can actually do. People to target may well be elected politicians (MPs, MSPs or Councillors). Others with a role to play may include journalists, officials and other disability organisations. You might form a coalition of disability organisations – and maybe other organisations too – to make your voice louder.

Why should they do what you want? Obviously you need a strong case but that may not be enough. If you want to influence people it is helpful to think about what motivates them. This may be something to do with their role. But it may also be to do with them as people. Like anyone else, politicians will be motivated by personal experience.

Also think about who else they are influenced by – perhaps journalists. You might want to target them as well. Think about what your organisations could offer them. For example, you might offer politicians your expertise in independent living, information about what's happening at the 'grass-roots', or new ideas about what works. You might offer them photo opportunities, or an opportunity to speak at your conference. Finally, think about the way in which you talk to them. People are sometimes rightly very angry about something that's happened. Of course, you need to be firm and get your points across, but shouting isn't likely to get you what you want (think about how you react when someone shouts at you!).

Taking action: It's not just a matter of recording the actions which caused the problem. You need to decide what action you are going to take to push for change. Thinking about what motivates your target/s and people with a role to play, what actions could you take to motivate them to do what you want? How will you know if the activity was successful?

The other thing to think about is when you're going to carry out the actions. There's always such a lot going on that it can be hard to get attention for your campaign. Are there any opportunities coming up that you could make use of? For example, these might be events or anniversaries.

Focusing your campaign

This section helps you to pull together all the thinking and planning to make sure your campaign is as focussed as possible. This is important because otherwise you risk wasting time and resources on actions without any clear outcomes.

Start by writing down your campaign objective. Now think about how to make it 'SMART' – S.M.A.R.T. You can use this as a checklist.

S is for Specific: Who specifically do you want to target? What specifically do you want them to do? Why specifically do you want them to do it? When specifically do you want them to do it?

M is for Measurable: How are you going to measure the success of your campaign? You might set targets for your activities and the changes that result from them.

A is for Achievable: There's no point spending time and money on a campaign that stands no realistic chance of success. What makes your campaign achievable?

R is for Resourced: Do you have enough people and money to carry out the campaign activities? If not, you'll need to think again.

T is for Timebound: There needs to be a start date and a finish date with a timetable of activities in between – otherwise the campaign will risk drifting on until it just fizzles out.

Campaign action plan

Finally it will help you to keep on track if you write down a plan of action. How will you launch your campaign? How will you finish it? What activities will you carry out in between?

Think about what order you will carry out activities. Remember to allow enough time to get everything organised. Try to make sure you keep the pace up or people may lose interest or get distracted by something else. You need to keep the pressure building!

Also think about who will be responsible for each activity. It's good to give everyone involved responsibility for something.

Write down:

- What activities will be carried out
- When each of them will be carried out

- Who will take responsibility for each of them
- How you will you measure the success of the activity
- What it will cost

Advocating for change

Independent advocacy means supporting people to be empowered, heard and respected. For example, it might mean working with someone – your advocacy partner - to push change or challenge the way they've been treated by a worker.

The approach is similar in lots of respects to the one described above.

- What are the **facts**? What exactly has happened?
- What does your advocacy partner need or want to happen? What is the **objective** or outcome that they're aiming for?
- Have you done an **analysis** of what human rights are relevant? What about other rights or laws?
- Have you **identified** who is responsible for the problem and who has the power to make positive change?
- What **motivates** them?
- What **actions** will could be taken to influence them? List them in order –and if possible say when each will be taken.

Conclusion

We hope you've found this tool-kit useful and that you'll be able to use it to take action to promote human rights to independent living. Disabled people have waited long enough to see their rights made into reality. The abuse of our human rights should not be allowed to continue.

If you have any comments or suggestions about this tool-kit, or any examples of when you've used human rights to promote independent living, please send them to Inclusion Scotland.

GOOD LUCK!

More information

Useful web-sites

Rights Commissions in Scotland

The Equality and Human Rights Commission Scotland site has a lot of useful information, advice and campaigns materials on human rights and on the UNCRPD <http://www.equalityhumanrights.com/scotland> . You will find an excellent guide to the UNCRDP at <http://www.equalityhumanrights.com/human-rights/a-guide-to-the-un-disability-convention/>

The Scottish Human Rights Commission (SHRC) has a general duty to promote and protect the human rights of everyone in Scotland, for example, by encouraging best practice in relation to human rights and by promoting awareness, understanding and respect for human rights, including a training and awareness resource: 'Care about Rights': <http://www.scottishhumanrights.com>

The following SHRC link takes you to a list of organisations that can help with human rights in Scotland:

<http://www.scottishhumanrights.com/abouthumanrights/helpwithhumanrights>

UK/Scottish Government websites

The Office for Disability Issues is part of the Westminster Government. It works across Government to promote disability equality. It has responsibility for co-ordinating work on the UNCRPD. Their web-site has information on the Convention, including some Easy Read versions. <http://www.odi.gov.uk>

The Scottish Government Disability Equality Scheme 2008-11: Annual Report 2010 is the government's statement on progress towards equality. See Chapter 5 in particular where they use the framework of the UNCRPD to report on action and progress.

<http://www.scotland.gov.uk/Publications/2010/12/24082632/11>

Other Information and Campaigns websites

The British Institute of Human Rights provides lots of useful information on human rights, including a tool-kit and a guide on human rights for disabled people, regular up-dates on human rights cases : <http://www.bihhr.org.uk/>

Centre on Human Rights for People with Disabilities provides lots of useful information and campaigns news: <http://www.disabilityaction.org/centre-on-human-rights>

Independent Living In Scotland have produced a useful guide to the UNCRDP at http://www.ilis.co.uk/uploaded_files/ilis_guide_no.2.pdf

Northern Ireland Human Rights Commission has developed an educational resource pack called 'Inspiring practice'. It includes resources, tools and activities to help people deliver workshops on human rights, including the Human Rights Act and the European Convention on Human Rights (ECHR): <http://www.nihrc.org/inspire>

Older People and Human Rights - report by Age Concern and The British Institute of Human Rights
<http://www.bihhr.org.uk/sites/default/files/Older%20People%20and%20Human%20Rights%20report-%20FINAL.pdf>

Campaign for a Fair Society is a new disabled people's campaign against the cuts: <http://www.campaignforafairsociety.com>

The UK Disabled People's Council has set up Rights Watch UK to collect evidence of whether the Government is complying with the UNCRDP. The website is: www.disabilityrightswatchuk.org

See The Bournemouth Case: rights for vulnerable people in the care system
<http://www.equalityhumanrights.com/human-rights/our-human-rights-inquiry/case-studies/the-bournemouth-case/>

International Advice and Information

You can find the full text of the UNCRPD and other useful information at the United Nations 'Enable' Site: <http://www.un.org/disabilities/>

A good general (short) guide to working with UN treaty bodies is prepared by the International Service for Human Rights: www.ishr.ch/guides-to-the-unsystem/simple-guide-to-treaty-bodies .

Parallel reports should be submitted to the secretariat of the CRPD at:

the UN Office of the High Commissioner for Human Rights:
CRPD secretariat, UNOG-OHCHR, CH-1211 Geneva 10, Switzerland

Email: crpd@ohchr.org

Visiting address: Palais Wilson, 52 Rue des Pâquis, 1201, Geneva, Switzerland
Website: <http://www2.ohchr.org/english/bodies/crpd/index.htm>

Tel: Mr. Robert Ouko, Administrative Assistant –CRPD: 0041229179703

Explanation of important words

Absolute rights: rights that can never be restricted in any way.

Article: a separate section

Inalienable: something which cannot be taken away or given away.

Limited rights: Rights which can only be restricted in specific situations, defined in the legislation itself.

Non-absolute rights: this includes limited and qualified rights.

Proportionate: reasonable, not excessive in the circumstances.

Protocol: an agreement that adds or amends

Public bodies or authorities: This includes National Health Service institutions, the police, schools, local authorities (including social work services), Scottish and Westminster governments. They also include residential care homes run by private or voluntary sector organisations under contract to a local authority. It is less clear whether it covers private and voluntary sector organisations delivering other services like education. Everyone who works for a public body has a duty to uphold the Human Rights Act.

Public function: The definition isn't always clear but roughly, these are roles or services which are the responsibility of central government, devolved governments or local authorities.

Qualified rights: rights that can be restricted to protect the rights of other.

Ratify: approve or confirm, officially sanction.