

Human Rights Materials for use by People with Learning Disabilities

1. Introduction

A key organising principle underlying the policy direction set out in Valuing People Now (DH 2009a) is that of 'rights' – that people with learning disabilities and their families have the same human rights as everyone else.

In the area of appropriate access to and support from mainstream health services, this has not always been the case in practice (Michael report 2008).

As well as the need to ensure that services recognise and respond to the rights of people with learning disabilities, it is important to help people themselves to understand and exercise those rights.

The Valuing People Now delivery plan (DH 2009b) states 'the Office of the National Director will commission a review of training materials on human rights and people with learning disabilities in order to identify gaps and good practice and will consider commissioning the development of additional training materials on human rights (review during 2009)'.

Training materials on human rights for support workers have been produced, and a suite of materials on human rights and a human rights based approach is to follow over the next 2-3 years. The first part of this is to develop human rights materials for use by people with a learning disability.

This small scoping exercise was commissioned to identify and review existing materials on human rights produced for people with a learning disability, highlighting good practice, and identifying areas not covered. The Our Way self advocacy group was asked to review some of the materials found, and to give their views about future needs for human rights materials.

2. Method

Email requests were sent to a range of potential informants, including existing networks (Foundation for people with learning disabilities, Paradigm); Valuing People Regional Leads, Partnership Board leads in England and personal networks of the people involved in the exercise.

A literature search was conducted using Medline, and hand searching recent journals (e.g. JIDR; JARID; BJLD) on internet publication sites; search of the BILD database; internet search using Google and Byng.

Each of the items was briefly described and reviewed by the researcher. A spreadsheet with this information was passed to a worker with Our Way, a self Advocacy group in Wyre Forest. They were asked to look at a selection of the materials and to comment on them, in terms of how easy they were to understand, how easy to use, and whether they were helpful in terms of building up a better understanding of Human Rights issues. The group was also asked to comment on what else might help in this understanding that they had not seen in the materials.

3. Findings

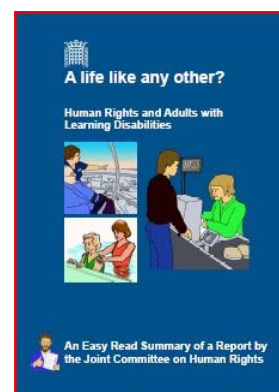
The materials found through the above method are presented below. There is a hyperlink to the material online where such a link exists.

For each, there is a brief description and a commentary. Where Our Way looked at materials, their commentary is added.

3.1 First, there were things that dealt with Human Rights generally

A Life Like Any Other? An Easy Read Summary of a Report by the Joint Committee on Human Rights

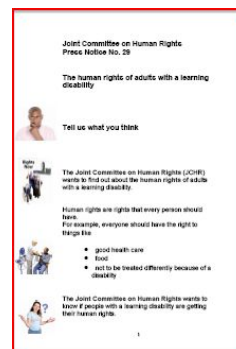
http://coventry.ldpb.info/images/Human_Rights_Act_for_LD.pdf



The Joint Committee reviewed evidence which shows it is still necessary to emphasise that adults with learning disabilities have the same human rights as everyone else. Recommendations include action to promote awareness and a positive approach to the rights of adults with learning disabilities under the Disability Discrimination Act 1995 (as amended) and the Human Rights Act 1998. This Easy Read summary is long (42 pages). It includes lots of information about the process of the review and the questions asked. It is a good starting point as to the importance of a human rights approach, but is also quite abstract in its ideas for use as a training aide.

Joint Committee on Human Rights Press Notice

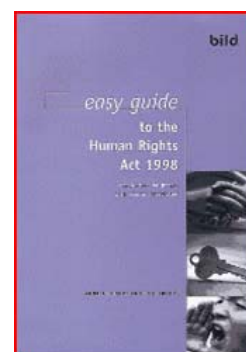
<http://www.parliament.uk/documents/upload/PN%2029%20-%20CfE%20adults%20with%20learning%20disabilities%20290307.pdf>



This is a brief introduction to the work of the joint committee using photosymbols pictures. It sets out some rights, and asks for people to get in touch to give their stories to the committee. It is out of date as the consultation is closed, but has enough information to be used as a brief introduction to the issues only.

Easy Guide to the Human Rights Act

Not available online



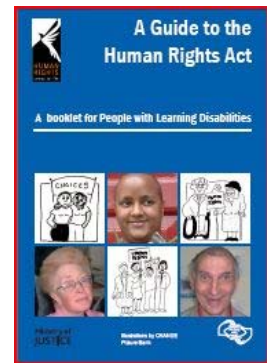
This guide was produced to highlight the key elements of the Act, and provides examples of how these can be applied to improving the legal rights of people with learning disabilities. It includes a number of real life stories/examples & suggestions for good practice. There is a poster which is useful as a reminder in workplaces/educational establishments etc.

This is a useful introduction to the Human Rights Act, but would need additional work on specific rights. The real life stories bring the Act to life in terms of the experiences of daily life for people. It would be possible to create a presentation out of the stories using 'PowerPoint' for training purposes.

The Our Way group looked at this. They thought the poster was quite dull and needed more colour and photographs. They also felt the book could have been in clearer English with less complicated words. Many of the group had switched off by the time they reached page 5. In terms of the usefulness for training, they scored it 2/3 out of 10.

A Guide to Human Rights Act: A Booklet for people with learning disabilities Ministry of Justice

[http://www.justice.gov.uk/news/docs/human-rights-act-learning-disabilities\(1\).pdf](http://www.justice.gov.uk/news/docs/human-rights-act-learning-disabilities(1).pdf)



Using illustrations from the Change Picture Bank this guide sets the act in the context of the workings of Government and democracy. Then each article is explained, with practical examples of how it might impact daily life. This guide also gives examples how the act should **not** be used.

This is a comprehensive guide that takes the reader through the backgrounds to the act, and sets out the context of how governments work, and what it means to be living in a democracy.

It is written in active language and short clear sentences.

The explanations are clear and appear pertinent to daily life.

Page 13 onwards looks at the operation of the act itself, in particular the responsibilities on public organisations, and ways in which individuals can bring the act to bear on those organisations if they break the law.

There is information on what the act means for the courts, as well as a brief mention of the impact in Scotland, Wales and Northern Ireland.

There is information about and links to organisations that can help

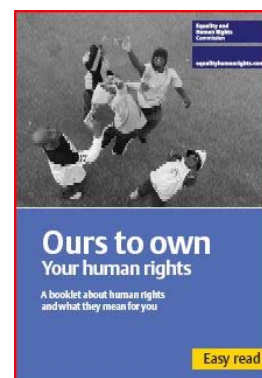
The document is 24 pages long, and covers a lot of ground. As such it would appear to be a good introduction to many issues, but may not be as in depth as required in relation to specific rights, as there is not enough space to deal with specific real life examples of rights being infringed or supported.

Whilst mentioning how the act cannot be used against other individuals in a legal sense, there is also not enough space to look at the responsibilities upon individuals to respect the rights of others.

The Our Way group also looked at this. Their response was much more positive, with comments like "Even the front cover makes you want to pick it up and look at it." They thought the information was clearly signposted and easy to find, with the pictures making things easy to understand. They suggested it would be good to have the information on a DVD with someone explaining it for those who can learn better this way. They scored with a clear 10 out of 10.

Ours to Own

http://www.equalityhumanrights.com/uploaded_files/publications/ours_to_own_easy_read.pdf



The act is covered clearly as a piece of legislation, as well as the role of the Equality and Human Rights Commission. The use of three stories should make this a good vehicle for discussion and debate about real daily life for people with learning disabilities.

Three rights are covered in more detail in the booklet - The right to life; to respect for private and family life and to dignity and being part of the community. Each of the rights is illustrated by a story:

Nina's story, which illustrates that that even though she had a disability, she had the same right to care and treatment as everyone else. Sarah's story, which illustrates that the right to respect for private and family life meant that Sarah and Judy (her partner) should not be treated differently from other couples Mary and Jean's story, which shows that all disabled people have the right to be supported to be a part of their local community

The Our Way group liked the cover of this, with one person saying they thought the pictures showed people reaching up like they are saying "give it to us" or "give us the world".

The idea of using bold type for some words and then explaining their meaning was well received. Whilst trying to cover the whole of Human Rights Act, using stories to illustrate specific issues was well received. One person said "I would choose this as it does not have too much information in." The group were a little divided, but scored this 7, 8 and 9 out of 10.

International agreement on the rights of disabled

People (Enable Easy Read Guide)

<http://www.inspireservices.org.uk/IS366%2007%20%20Easyread%20UN%20Convention%20on%20Human%20Rights%20FINAL%20low%20res%205%20Dec%2007.pdf>

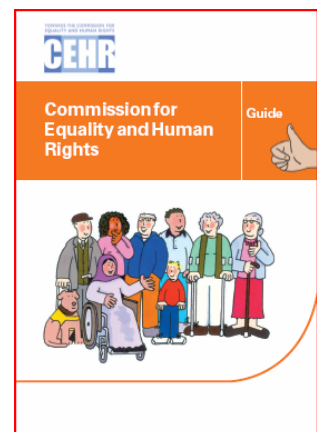


This is a long document (57 pages) which covers everything that is found in the International agreement. It defines key words and basic ideas and sets out what how the agreement will be put into practice. There is a lot about international agreements and how this will work in implementing the agreement over time.

The sections include: Equal treatment for women with disabilities, children with disabilities, information about disability, being treated equally by the law and getting justice, independent living and being a part of the community, getting about, privacy and respect for the home and the family, education, health and work etc.

It is a comprehensive document which could be used for reference purposes, but it is unwieldy and often feels that it is operating at a 'high level'. It is good on stating principles and what should happen, but it less good on giving concrete examples that can be used in local discussion.

Equality and Human Rights Commission: Easy Read Guide



Guide to what the commission is, what it will do and how it will work. It also has a list of words used with definitions. The guide uses coloured line drawings to give examples. The examples used are still quite abstract in places, and the sentences are quite long. It would be good for an introduction to what sources of support exist and how to get help when you need it.

Rights For All: People with learning difficulties using the Human Rights Act, Values into Action

Not available online but can be ordered from:

<http://www.viauk.org/>

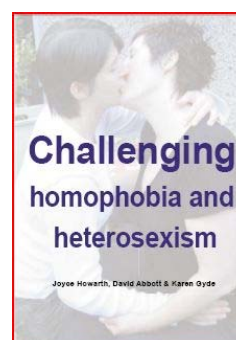


This is the report of VIA's Rights for All Project which ran from 2003-2005. The project team visited over 30 advocacy groups capturing people's experiences and stories in relation to human rights. Whilst there is a section which uses Change Picture Bank drawings to explain the articles of the act, the aim of the booklet is to describe the project, its findings, and discuss the implications of those findings. It is mainly text based and would be better suited for use by supporters, although there are a number of stories/role plays that could be adapted as excellent learning tools for people with disabilities.

3.2 Then there were things that dealt with specific rights

Secret Loves Hidden Lives

<http://www.bristol.ac.uk/norahfry/research/completed-projects/challenging.pdf>



This booklet focuses on the specific issue of relationships, sexuality and the right to a private life, freedom of expression and freedom from discrimination on the grounds of sexual orientation. Following a text based introduction to the research, there is a series of large photos with questions relating to how the viewer feels about the people in the pictures, which can challenge the viewer's attitudes to homosexuality.

The Our Way group did not really understand the title of this booklet, and most said they would not have picked it up to look at if they had not been asked to do so for this session. They felt that it would be useful to use in a group, perhaps in small workshops using role play. They gave this 4 out of 10. However, they also looked at Jan's story, the accompanying booklet and were much happier with this approach.

Jan's Story

<http://www.bris.ac.uk/norahfry/research/completed-projects/jan.pdf>



As follow up to 'challenging homophobia'. Picture story of what happens to 'Jan' at her day service. The recommendation in the introduction is that the story can be used with for women and men who are 'questioning' their sexual identity, but also can be used with all people with learning difficulties. The Our Way group really like this and felt they wanted to use it. One person commented they really learned something from the booklet. They found it easy and colourful and gave it 10 out of 10.

Phil's Story

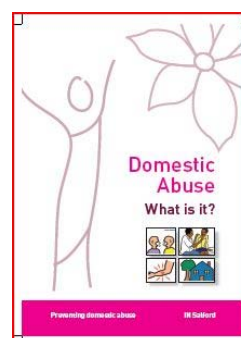
<http://www.bris.ac.uk/norahfry/research/completed-projects/phil.pdf>



As follow up to 'challenging homophobia'. Picture story of what happens to 'Phil' at his day service. The recommendation in the introduction is that the story can be used with for women and men who are 'questioning' their sexual identity, but also can be used with all people with learning difficulties.

Domestic Abuse What is it?

<http://www.easyhealth.org.uk/FileAccess.aspx?id=2270>



This leaflet was produced in Salford and explains different forms of domestic abuse, giving advice about what to do if someone thinks they might be a victim of abuse. It is aimed at individuals who may be suffering domestic abuse and also provides information specific to Salford, which might be confusing. It could be adapted for use more broadly.

Abuse: Stop it Now!

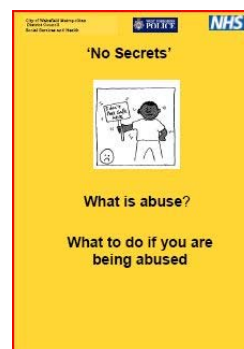
<http://www.easyhealth.org.uk/FileAccess.aspx?id=741>



Produced by Working with Words for Greenwich Council using photos to illustrate bullying, physical abuse, emotional abuse, financial abuse, neglect and sexual abuse. Each issue has a brief explanation. There are links to local help at the end of the document. It uses very clear one sentence descriptions with powerful photographs that would be an excellent starting point for discussion with people. It focuses on one major theme, and specific issues within that theme. There are contact numbers for help at the end, which are Greenwich based.

No Secrets

<http://www.easyhealth.org.uk/FileAccess.aspx?id=2076>

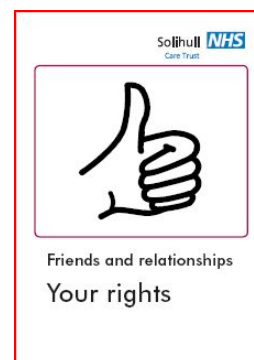


Produced with illustrations from the Change Picture Bank for Wakefield Health and Social Care with West Yorkshire Police, this document describes forms of abuse, talks about where it might happen and provides advice on what to do, with local links to information and help.

The Change picture bank drawings do not seem as powerful as the pictures used in the Greenwich leaflet. The explanations of forms of abuse are clear, and there is advice about what to do if you feel you are the victim of abuse. There are Wakefield based contact details.

Friends and Relationships

Not available online



Produced by Solihull Care Trust, a series of booklets using line drawings to explore rights and responsibilities with regard to friendships and relationships. They are clearly written and of a good manageable length. The series covers:

- i. Your Rights: sets out rights and responsibilities to be aware of other people's rights. Has a section on confidentiality.
- ii. Friends: making friends, being a good friend, staying friends
- iii. Being safe: what it means, things to do to keep safe, safe sex,
- iv. Relationships: different kinds of relationships, clarifying role of support worker with regard to relationships
- v. People who can help: talking to people you trust, and who you can talk to
- vi. Masturbation: privacy, appropriateness and personal hygiene.

The text is clear and the line drawings are appropriate for the subject matter. Although produced in Solihull, they would have application elsewhere.

The Our Way group liked these leaflets, saying they were attractive and most would have picked them up to look through. They were described as simple and easy to use, with just enough information; not too much. They felt the information in booklets could usefully be used as a power point presentation. They gave these booklets 10 out of 10.

Look North: news feature on disability hate crime

<http://www.arcsafety.net/page1/page8/files/page8-1002-pop.html>



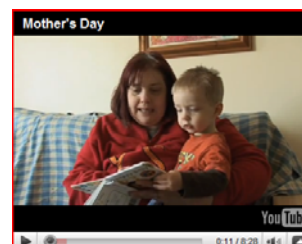
This is a news item from Look north, a local BBC news bulletin which includes some footage from training, interviews with victims and local police (found on Safety Net website). It is clearly narrated throughout. It follows the experience of one couple to illustrate the issue, and this seems to work well. There is enough content to get support discussion.

We asked the Our Way group to look at this video, but unfortunately the computer they had during their session was not able to play it. This raises some

questions about whether people are able to see videos placed on websites if they do not have the appropriate software.

Mother's Day

<http://www.bihhr.org.uk/policy-and-public-affairs/human-rights-documentaries-from-the-isis-film-project>



This is a video produced by the British Institute of Human Rights (BIHR) featuring the story of Marie, whose son is subject to a care order. The video follows her and her partner to family court to get the care order lifted. The video also describes what happened with her first two sons who were taken into care.

The video feels quite long (although only 8.5 mins.) and has a lot of footage of Marie with her son, which is helpful in getting to know her and her situation, but it may be quite difficult to move from this to the specific discussion of rights. It clearly explores the right to family life, so could be useful when looking at this specific issue.

Bournemouth Judgement

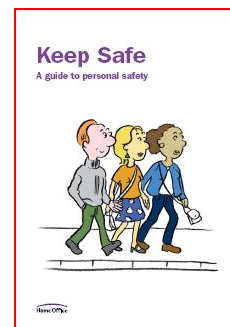
<http://www.equalityhumanrights.com/human-rights/human-rights-inquiry/case-studies/the-bournemouth-case/>



A video from the Equality and Human Rights Commission (EHRC) narrated by Mr & Mrs E., family carers of HL, a man with autism spectrum disorder who was detained in Bournemouth hospital in 1997, following an incident on the bus on the way to the day service. The European Court of Human rights found that HL had been detained illegally, which led to the introduction of the deprivation of liberty safeguards. The video touches on many issues relating to the deprivation of liberty. It could be useful for staff as a basis for discussion as it is mainly talking alongside a montage of images, exploring the personal fight of the family involved to ensure HL got the support he needed. It is not clear that this would be a useful video specifically for people with learning disabilities.

Home Office Guide to Keeping Safe

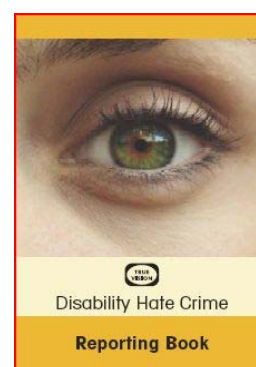
<http://www.arcsafety.net/page7/assets/keepsafe.pdf>



Home Office Guide to 'keeping safe' setting out practical steps to take at home, in the street, at work etc. It is very bright and colourful with lots of practical advice. Clearly it is focused on one issue, but could be useful as part of a later discussion following a broader introduction to Human Rights and the Act.

Disability Hate Crime Reporting Book

http://www.arcsafety.net/page7/assets/Hate_Crime_Reporting_Book.pdf



This booklet uses pictures to set out key rights, information on how to keep safe and use the law. It focuses on how to report disability hate crime, with information on how to contact the police, and what will happen when you do. It also discusses the role of the Crown Prosecution Service.

It has links to those organisations, and others that can help. It is very clear and colourful, which creates a good impact. Geared towards advice and guidance to people on what to do about reporting disability hate crime, it is very clearly focused. It may be too specific for this purpose, but again would be useful as part of ongoing support to people in understanding their rights and acting on instances when those rights are curtailed.

Disability Equality Duty: Easy Read Guide

<http://www.ncil.org.uk/ULOUploads/BPF%20DED%20DC6.pdf>



Using pictures, a leaflet style document explaining the Disability Equality Duty, and the responsibility on public services to ensure disabled people have the same rights as other people

It is clear and concise, mainly pointing out what public agencies need to do in relation to accessible services. Produced in Bath, and aimed at getting people involved locally. It may be too specific to be useful in this context.

3.3 Finally, we also found examples of projects that were working with human rights, either in training, or in introducing human rights as an operating principle for things like risk assessment and risk management.

In Cornwall, courses were run for people with learning disabilities over a period of time based on human rights, which used a range of resources. Following an initial skills assessment the course had sessions on 'self-esteem', 'assertiveness', 'what behaviour is and where it comes from', 'feelings', 'our rights', 'saying yes and no', 'presenting ourselves', - feeling good about yourself, 'soft skills'- interpersonal relationship management, making a choice, going to a meeting, what is important to me - what do I want to do? The course explored issues as they arose, and used posters, handouts and video clips.

In Merseyside, the Mersey Care NHS Trust has produced a risk management system based on a human rights approach. A Joint Risk Assessment and Management Plan (JRAMP) tool evaluates the extent to which human rights are incorporated into the lives of people supported by complex care pathways, and the extent to which a human rights based approach is taken by the services they use.

A 'keeping me safe and well' screen is used, which uses a traffic lights approach to help identify risks, using red for those risks that people are really worried about, amber where people are worried 'a bit' and green where they are not worried at all. Staff also look at the likelihood and severity of the risk to the person, and score this accordingly. Under each risk section Human Rights issues are listed and staff are expected to point out the important Human Rights as they go through the assessment with the person.

The documentation available is not for training purposes, but is an assessment tool to be used with people to identify and appropriately manage risks, but worthy of bringing to the attention of the project as a practical example of the use of a human rights approach in supporting people with complex healthcare needs.

4. Discussion

This scoping exercise set out to identify materials relating to human rights issues that had been produced for use by people with learning disabilities. The project only had a short space of time, and there may well be things in use that were not found.

There seem to be some good booklets produced by the 'Equality and Human Rights Commission' and the 'Ministry of Justice'. Self Advocates from Our Way gave these booklets 7 or 10 out of 10.

These booklets talk about the Human Rights Act, but they also use stories to help people to understand what some of the rights mean.

We found some things that talked about certain rights like relationships and sexuality. Some of the words used in one of these booklets were confusing. However, when the authors used a story (Like Jan's Story) people liked them and thought they were helpful for challenging ignorance.

The self advocates liked the leaflets produced by Solihull NHS Trust looking at relationships very much. These leaflets were small and had just the right amount of information in them.

The self advocates in the Our Way group wondered if there was a better way of learning about Human Rights, for example using Videos or DVD's, Role Play, Workshops and Drama Groups.

Unfortunately, the group could not look at one of the videos on the internet, as the computer they had would not show it. This can be a problem with videos on websites.

It was interesting that the Our Way group said they had not really thought about Human Rights as a topic before being asked to look at the books and leaflets. They thought they might need more opportunities think about it, and learn some more.

Most of the books and leaflets had addresses, phone numbers and websites where people could go for more information. The self advocates thought this was a good idea, because it meant they knew where we to go to get more information about Human Rights.

We were also able to find some projects that were using a human rights framework to develop approaches to risk management, such as the project in Merseyside, and a training programme in Cornwall that used a variety of local materials to discuss human rights issues. This latter course chimed very much with the feedback from self advocates which suggested a multi-media, multiple

method approach to learning about human rights. This would involve the use of accessible materials, but in the context of broader training framework.

5. Recommendations for Development

Based on what was found in the short time we had available, and on feedback from the self advocates in the Our Way group, the following recommendations for development are suggested.

- i. Use existing guidelines for making information accessible to people (see for example Easy info guides <http://easyinfo.org.uk/dynamic/easyinfo46.jsp>)
- ii. Break down the messages into bite size pieces. The Human Rights Act is complex with many articles and protocols.
- iii. Where possible, use single leaflets for single issues.
- iv. Use lots of pictures that illustrate what is being said.
- v. When describing and explaining rights, use stories to illustrate what this might mean on a daily basis
- vi. Use video and audio materials to describe and explain rights and to tell stories.
- vii. Use Role Play, Workshops and Drama with groups.
- viii. Always provide contact details of people who can help – most people said they wanted to have the chance to talk to people about the issues after they had read the booklets or had some input from trainers.

References:

Department of Health (2009a); Valuing People Now, HMSO

Department of Health (DH 2009b); Valuing People Now Delivery Plan, HMSO

John Northfield December 2009