A teacher’s guide to disability and oral history
by Alex White, Philip Mann and Richard Rieser

SPEAKING for OURSELVES

Time to get equal

www.speakingforourselves.org.uk
Speaking for Ourselves may prove to be one of the most important projects Scope has ever undertaken in its half a century of existence.

First, because as the project's title implies, it will enable the many voices of the people Scope empowers to be heard better – more clearly, more effectively and more passionately – by a wider audience than ever before. This is important, particularly to those at school still learning about society and life and their role in it, because the history of disabled people is a vital part of the history of us all.

Second, because oral (and visual) records of people's lives are one of the most powerful tools in helping us understand each other better. It is easy to pass a disabled person by in the street without making contact; it is nearly impossible to hear and see that same person talking openly about their lives without being in some way changed forever and for the better. The project will make that happen.

Thirdly, without a record of the past and its inhabitants we who live now have no touchstone for the present and future. The young learn from the old, often despite themselves and without quite realizing it, and everybody benefits. Each time someone with cerebral palsy dies without leaving a record of themselves and what life meant for them a treasure house is lost. Speaking for Ourselves is about making that treasure available to all.

Fourthly, and speaking personally as a professional writer, oral history archives are a vital part not only of resurrecting the past for present consumption but of getting it right, or telling the truth. This project will enable those who know the truth to tell it now and for the future.

And finally, we should remember that that future may easily include an individual with cerebral palsy not yet born who one day, decades hence, will be able to listen to someone older tell it like it was because of Speaking for Ourselves. I think we can reasonably say that they may gain not only comfort and inspiration but also the sense that they are part of a wider community that cared enough to make it possible for the voice of the past to be heard for all time.

William Horwood
1. Introduction by Richard Rieser

Speaking for Ourselves will provide a timely resource as schools in England, Scotland and Wales prepare to gear up to the duty to promote disability equality. The public sector duty will require all schools to have a Disability Equality Scheme. The scheme will need to show how the school will eradicate disability discrimination both in employment and the delivery of education and associated services, admissions and exclusion. The school will need to show how it eliminates harassment against disabled people and how it plans to promote disability equality.

Schools will need to identify all disabled pupils and staff and monitor their progress. Remember that the Disability Discrimination Act definition (see glossary) goes much wider than what most people consider disabled people, including people with HIV/Aids from the point of diagnosis to those recovering from cancer, from those with learning difficulty or challenging behaviour due to an underlying condition. Currently around 7% of pupils in mainstream schools are likely to come under the definition (this is rather arbitrarily made up of those on school action plus and statemented pupils).

Covering the subject matter contained here and on the DVD will ensure disability is covered fully in different parts of the curriculum:

- Citizenship in KS3 & 4
- Personal Social Health Education in KS2 & 3
- History (using the interviews as a primary source)

By regularly including the experience of disabled people and the changes in their lives will help to promote disability equality and help break down the barriers to valuing difference that still exist.

In some ways we have moved a long way from the experiences recounted by the participants in the project who struggled to assert their humanity against an unyielding system which only viewed disabled people through the lens of the ‘medical model’. What disabled people could not do was the focus (rather than what the barriers were) that prevented us being included and the support we would need. It is a testament to the human spirit that so many of the participants achieved so much despite there being no effective legislation. Scope has adopted the word ‘disability’ to describe the systematic oppression and discrimination that disabled people have faced and unfortunately still do face too often (as can be seen in our Topic Sheets). The Time to Get Equal campaign is one of many initiatives that are addressing this inequality. The Government’s ‘Improving the Life Chances of Disabled People’ and the widening of the Disability Discrimination Act are two others. At the United Nations over the last five years a negotiation, which has included representatives of disabled people for the first time, is nearing completion to give the world the UN Convention on the Rights of People with Disabilities.

All of these initiatives spring from a transformation in thinking about disabled people – the move from a medical model approach, which view the problem as the disabled person’s impairments, to a social model approach, which views the issue as one of equality and the need to remove barriers. These are barriers of environment, social organisation and attitudes. Their removal and the provision of support so disabled people can participate equally in education, employment, family life, leisure, transport, political life and the media remains one of the great challenges of the 21st century. In the Topic Sheets, we provide activities which will help pupils and students develop this shift in their thinking.

The oral history recounted here can be located against the timeline, which demonstrates this shift that has been underway for the last 30 years. The experiences recounted are a concrete resource that can be used to gain an appreciation of the need for disability equality, which can be used with pupils at all levels. We provide some ideas of how these resources can be used, but teachers will be able to adapt and use these materials to fit into schemes of work and lesson plans in myriad ways.

Part of this transformation has been the development of inclusive education, which although only well established in a minority of schools, has widely developed in the last 15 years. What teachers and those who work alongside them need is the leadership and support of their senior colleagues to:

- give support and credence to pupils’ and parents’ views,
- collaborate with professionals from outside the school, and
- take account of the diverse ways and timing of learning for different pupils
- develop peer support

Integration is about one size fitting all, but inclusion is not. Inclusion is about restructuring to remove the barriers within the school so that all pupils can achieve and flourish. This therefore does not mean all pupils doing the same activity at the same time or in the same way. For example, a pupil in Year 9 Science with significant learning difficulties can be working in a group doing an experiment as the timekeeper, as this is on her Individual Education Plan target. Another approach would be for the teacher to identify the essential knowledge or understanding they want all the pupils achieve and present it in a way that they all can by having a range of activities to suit the learning styles and aptitudes of the different students in the group.

These were some of the findings of the Reasonable Adjustment Project, which examined how 40 different schools were meeting the needs of the DDA and developing inclusion. This useful training pack can be ordered free to schools from the DfES under the title ‘Implementing the Disability Discrimination Act in Schools’.

Though we would hope things have progressed for disabled young people today, the evidence is still there of underachievement, bullying and segregation of disabled pupils. This pack and the materials it contain will help address the need to promote disability equality and inclusion in our schools.
The ‘medical model’ sees disabled people as the problem. They need to be adapted to fit into the world as it is. If this isn’t possible, then they should be shut away in a specialised institution or isolated at home, where only their most basic needs are met. The emphasis is on dependence, backed up by the stereotypes of disability that bring out pity, fear and patronising attitudes. Usually, the impairment is focused on, rather than the needs of the person. The power to change disabled people seems to lie with the medical and associated professions, with their talk of cures, normalisation and science. Often, disabled people’s lives are handed over to these professionals. Their decisions affect where disabled people go to school; what support they get; where they live; what benefits they are entitled to; whether they can work; and even, at times, whether they are born at all, or allowed to have children themselves.

In addition, the disability movement points out how the built environment imposes further limitations on disabled people. Medical model thinking would say these problems are due to the disabled person’s lack of rehabilitation. The disability movement perceives the difficulties disabled people experience as the barriers that disable them and curtail their life chances. These difficulties include in school and higher education, in finding work and suitable work environments, accessing leisure and entertainment facilities, using private and public transport, obtaining suitable housing, or in their personal, family and social life.

Powerful and pervasive medical model views are reinforced in the media, books, films, comics, art and language. Many disabled people internalise negative views of themselves and develop feelings of low self-esteem and underachievement, which reinforce non-disabled people’s assessments of their worth. The medical model, plus the built environment and social attitudes it creates, lead to a cycle of dependency and exclusion that is difficult to break.

This thinking predominates in filmmaking, leisure, work and education. In schools, for instance, special educational needs are considered the problem of the individual, who is seen as different, faulty and needing to be assessed and made as ‘normal’ as possible.

Increasingly, today, the medical model is being rejected. Many people feel strongly that treating disabled people as needing to be adapted to existing circumstances or, if this is not possible, caring for them in specialised institutions, is wrong.
The 'social model'

In recent years, the disability movement has advocated a different way of looking at disability, which they call the 'social model'. The distinction has been made between impairment and disability:

"Impairment is the loss or limitation of physical, mental or sensory function on a long-term or permanent basis. Disablement is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers."

Disabled People's International 1981

This starts from the standpoint of all disabled people's right to belong to and be valued in their local community. Using this model, you start by looking at the strengths of the person with the impairment and at the physical and social barriers that obstruct them, whether at school, college, home or work.

Impairment and chronic illness exist and sometimes pose real difficulties. Supporters of the disability movement believe that the discrimination against disabled people is socially created and has little to do with their impairments, and that, regardless of the type or severity of their impairments, disabled people are subjected to a common oppression by the non-disabled world. Disabled people are often made to feel it's their own fault that they are different. If some part, or parts, of your body or mind are limited in their functioning, this is simply an impairment. It doesn't make you any less human. But most people have not been brought up to accept all people as they are; in other words, to value difference. Through fear, ignorance and prejudice, barriers and discrimination develop that disable some people. These are often reinforced by images in the media.

Understanding this process allows disabled people to feel good about themselves and empowers them to fight for their human rights.

The 'social model' approach suggests disabled people's disadvantage is due to a complex form of institutional discrimination, as fundamental to society as sexism or racism. The disability movement believes the 'cure' to the problem of disability lies in changing society. Unlike medically-based cures, this is an achievable goal and benefits everyone.

The obsession with finding medically-based cures also distracts people from looking at the causes of impairment or disablement. In a worldwide sense, most impairments are created by wars, hunger, lack of clean water, exploitation of labour, lack of safety and child abuse. These should be addressed more robustly, rather than just responding to the injuries and impairments that result from them.

In 'Improving the Life Chances for Disabled People' (2005), the Prime Minister's Strategy Team acknowledges the power of social model thinking in eradicating disability discrimination.

### MEDICAL MODEL THINKING

- child is faulty
- diagnosis
- labelling
- impairment becomes focus of attention
- assessment, monitoring, programmes of therapy imposed
- segregation and alternative services
- ordinary needs put on hold
- re-entry if normal enough or permanent exclusion
- society remains unchanged

### SPECIAL MODEL THINKING

- child is valued
- strengths and needs defined by self and others
- identify barriers and develop solutions
- outcome based programme designed
- resources are made available to ordinary services
- training for parents and professionals
- relationships nurtured
- diversity welcomed child is included
- society evolves

Adapted from Micheline Mason 1994, R Rieser 2000

### Challenging prejudice

#### Medical and social model thinking in schools

Social model thinking has important implications for the education system, and particularly primary and secondary schools. Prejudiced attitudes toward disabled people and all minority groups are not innate. They are learned through contact with the prejudice and ignorance of others.

Therefore, it is appropriate that the challenge to discrimination against disabled people should begin in schools. The fight for the inclusion of all disabled people, however severe their impairments, in one mainstream social system, will not make sense unless people understand the difference between the social and medical models of disability.

The social model has now been adopted by the World Health Organisation.
Oral history is the recording of people’s memories. It is the living history of everyone’s unique life experiences.

Oral history is new and exciting because it is interactive: it is shared history and a rare chance to actually talk to history face to face.

Oral history preserves everyone’s past for the future.

To find out more, visit the website of the Oral History Society at www.ohs.org.uk

3. What is oral history?

Identifying the barriers: finding solutions exemplar

The language we use

Language is important in all equality agendas, and disability is no different. We use the terms 'disability' and 'impairment' quite separately. Most people have an impairment, however minor – but they are not disabled unless there is a negative social response to them because of the impairment. For instance, a person with impaired vision requiring reading glasses would not see themselves as disabled if they lived in the UK. But if they lived in a rural area of Africa they may well be, as they might have been excluded from a proper education and would find it more difficult to find employment.

Disability describes how society responds to people with impairments; it is not a description of a personal characteristic. A disabled person is not a ‘person with a disability’ as the person does not own the disability in the way that you might be ‘a person with brown hair’. The opposite of disabled is not able-bodied or abled - it is non-disabled or enabled.

This list reflects the views of disabled people themselves. As you will see, the words on the left are passive, victim words, whereas the words on the right respect disabled people as active individuals with control over their own lives.

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<tr>
<th>AVOID</th>
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<td>(the) handicapped</td>
<td>disabled people</td>
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<tr>
<td>afflicted by, suffers from, victim of</td>
<td>has (condition or impairment)</td>
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<tr>
<td>confined to a wheelchair, wheelchair-bound</td>
<td>wheelchair user</td>
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<tr>
<td>mental handicap, subnormality</td>
<td>learning disability/learning difficulty</td>
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<tr>
<td>cripple, invalid</td>
<td>disabled person</td>
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<tr>
<td>spastic</td>
<td>person who has cerebral palsy</td>
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<tr>
<td>able-bodied</td>
<td>non-disabled</td>
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You can get more material and information on this thinking from: www.diseed.org.uk and www.scope.org.uk/issues/tellitlikeitis/index.shtml

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Oral history records people’s experiences on sound and video tape. It is a vital tool for our understanding of the recent past. No longer are we dependent only on the written word.

Oral history enables people who have been hidden from history to be heard, and for those interested in their past to record personal experiences and those of their families and communities.

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4. Guidance for oral history interviewers

The most important things to remember during the interview:
- Choose a quiet place and be aware of things like traffic noise, other people, pets or equipment in the room.
- Sit facing the interviewee, at a slight angle. Sit as close as possible, but at a distance that feels comfortable to you both.
- Ask the interviewee if they have a mobile, and if they could switch it off during the interview. If on, it might cause tape interference and could disturb the flow of the conversation if it rings.
- Set up the recorder so it’s not directly between you and the interviewee. You will need to be able to see the recorder. It helps people to forget that they are being interviewed.

**Listen**

Ask questions according to the replies, rather than the any list of prepared questions. You may want to have a list of questions close to hand but only use them if you are stuck. The aim is for the interviewee to do the talking.

If you feel there may be more that the interviewee wants to say, but they have finished a reply, then you can ask things like “How did that feel?”, or “So what happened next”? or “Why was that?” These questions can give to interviewee more chance to finish covering a particular theme.

**Get lots of detail**

The best approach is to reassure the interviewee that we are seeking a lot of detail in the interview. Listen very carefully to each answer and form your next question from that. Ask for additional information as precisely as possible, but be careful to ask open-ended questions which invite description, comment and opinion. Avoid questions which may be likely to produce only a ‘yes’ or ‘no’ answer. Remember not to phrase questions in a way that suggests the answer. Be neutral in style. So, for example, rather than asking ‘I suppose you must have had a poor and unhappy childhood?’, ask ‘Can you describe your childhood?’

**Let things flow**

It doesn’t matter if the recording isn’t strictly chronological. If the conversation jumps time, or changes to another topic, don’t worry. If possible, bring the interview back to a logical time frame later. This can be after a break or at the beginning of the next interview session. Be aware of any gaps in testimony, so that nothing is missed. You may have to fill in any gaps later, but the most important thing is to listen to what’s being said, and to respond to the opportunities presented by the telling of a memory-rich part of the life story.

**Fact and opinion**

All memories are a mixture of fact and opinion, and both are important. It’s important to get direct personal experience, rather than things that might have been heard second-hand.

**Don’t do the talking**

It is important to get the interviewee talking. You need to remain quiet during replies, and please try to avoid accidentally speaking over what the interviewee is saying. Remember not to come in with your next question too soon after the interviewee has apparently finished. This is just in case they continue unexpectedly. In response to an answer, smile, or nod, but please avoid making any encouraging noises or comments.

**Memory joggers**

Memory joggers may be useful, but not essential. The most convenient are photographs, though it will depend on the preference of the interviewee. Ornaments or other mementoes may be useful memory joggers, though don’t encourage them to be physically handled by you or by the interviewee. Things may be on display in the room, which you can refer to in conversation. Be careful about handling photographs as well, especially if they are fragile. Watch out for liquids. When you talk with the interviewee a few days before you visit, it may be best to check if the interviewee is prepared to have photos to hand.

Go to www.speakingforourselves.org.uk to download:
- Oral history interviewers’ manual
- Copyright form
- Speaking for Ourselves question scheme – part one
- Speaking for Ourselves question scheme – part two
5. Disability and cerebral palsy glossary

**Ataxic cerebral palsy**
A form of cerebral palsy characterised by problems with balance, co-ordination, shaky hand movements and jerky speech.

**Athetoid cerebral palsy**
A form of cerebral palsy characterised by involuntary movements resulting from the rapid change in muscle tone from floppy to tense.

**Cerebral palsy (cp)**
Cerebral palsy is a physical condition that makes muscles hard to control. It doesn't necessarily make you less intelligent, but it can make it very hard to communicate or get around by yourself.

**Disability**
Definition of Disability Discrimination Act (DDA): “A disabled person is defined as someone who has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.” The Government thinks 7% of pupils in schools come under this definition.

**Disability Discrimination Act 1995 (DDA)**
The first significant piece of legislation to prohibit discrimination against disabled people and was an important step forward in the campaign for full civil rights for all disabled people.

**Hemiplegia**
Where one side of the body is affected.

**Paraplegia**
Impairment of legs only.

**Physiotherapy**
Treatment of disorders of movement and function by exercise, manipulation, heat or ultrasound.

**Quadriplegia**
All four limbs affected.

**Scope (formerly The Spastics Society)**
Scope is a national disability organisation whose focus is people with cerebral palsy. Our aim is that disabled people achieve equality.

**Spastic cerebral palsy**
The most common form of cerebral palsy where some muscles become very stiff and weak.

**Speech and Language Therapy**
Therapy to assist with communication, eating and drinking difficulties.

**Time to Get Equal**
Scope’s mission is to drive the change to make our society the first where disabled people achieve equality. Find out more about disablism at [www.timetogetequal.org.uk](http://www.timetogetequal.org.uk)

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**Count Me In**
Video of six primary and six secondary schools in England and Wales that are developing inclusive practice. First screened on Channel 4. 55 minutes. Available from DEE, £10.

**Implementing the Disability Discrimination Act in Schools**
DfES 2006. Pack including 5.5 hours of DVD on inclusive practice.

**Oral history of Scope**
To celebrate its 50th anniversary, Scope commissioned freelance journalist Chris Davies to produce an oral history of Scope entitled ‘Changing Society’. It is based on interviews with 17 individuals, the majority of whom, like Chris, have cerebral palsy and have played a significant role in the organisation’s development or who have strong opinions about it.

The 168-page book can be downloaded free from [www.speakingforourselves.org.uk/resources/index.shtml](http://www.speakingforourselves.org.uk/resources/index.shtml)

"Can you manage stares?: the life of Bill Hargreaves"
Bill Hargreaves was a founding member of Scope. When Bill Hargreaves was born in Australia in 1919, he weighed just two and a half pounds. His parents were told that, because he had cerebral palsy, he would ‘never walk or work or wed’. Bill’s remarkable life defied the doctor’s diagnosis. Bill became a campaigner for disabled people’s right to work. It was the start of his pioneering work, which was to open up employment, recreation and travel to vast numbers of disabled people both in this country and many others around the world.


See the Speaking for Ourselves website for the collected life stories from the project as well as details of how to obtain further free copies of this material, or to enquire about disability equality training. All audio interviews from Speaking for Ourselves will be held at the British Library Sound Archive at [www.bl.uk/collections/sound-archive/disability.html](http://www.bl.uk/collections/sound-archive/disability.html) (type “C1134” in the search box), where you can also book an appointment to hear the interviews in full.

6. Further resources

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One in 400 babies born in the UK has cerebral palsy.

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FILM
Archived film footage from Scope and the Speaking for Ourselves DVD is held by the British Library Sound Archive, British Film Institute and Wellcome Library.

There are a number of films portraying disabled people, some truthfully; some less so! For more details, try ‘Disabling Imagery: A teaching guide to disability and moving image media guide’ (2004) Written by Richard Rieser and published by Disability Equality in Education, with support from the British Film Institute. (ISBN 0954720105) Or visit www.bfi.org.uk/disablingimagery

ORAL HISTORY TITLES

Talking in class: oral history and the national curriculum, Allan Redfern. Essential for oral history projects planning to work with schools and described as a vital manual for teachers. Oral History Society, 1996. ISBN: 0950780472. To order a copy, contact Webscribe on 01442 879097 or email subs@webscribe.co.uk

Doing Oral History: A Practical Guide


Disability collections at the British Library Sound Archive are at www.bl.uk/collections/sound-archive/disability.html

More resources can be found at the Oral History Society’s website at www.ohs.org.uk/resources/

LIFE STORIES OF PEOPLE WITH CEREBRAL PALSY

I, Alison – Reaching for a Life of My Own

Autobiography of Alison French who has cerebral palsy and is the subject of BBC documentaries.

I Can't Walk But I Can Crawl

Joan (who appears on the Speaking for Ourselves video) describes her childhood, her development as a teenager and her adult life.

Inner Vision

Undefeated

Two autobiographies by Dr Lin Berwick, MBE (who appears on the Speaking for Ourselves video).

My Left Foot

Autobiography describing the childhood and adolescence of Christy Brown, from his birth with cerebral palsy in Dublin in 1932. He recounts his childhood struggle to learn to read, write, paint and finally type, with the toe of his left foot. The book was made into a film with Daniel Day-Lewis.


Gail Taylor was born with cerebral palsy in 1951 and soon became visually impaired. Later, Gail learned to converse in seven languages.

Uphill All The Way

Sticks and Stones: The autobiography of John Hawkridge

One Step at a Time – Emmett My Son’s Battle to Walk

Paula’s Story

Doran – Child of Courage

So Clear in My Mind
Alan Counsell, Hutchinson, 1982. ISBN: 009149690X. Alan (who appears on the Speaking for Ourselves video) is a teacher, adviser and councillor, who was born in Blackburn in 1937 with what was later discovered to be cerebral palsy.

To The Mountain Top

White On Black

POETRY/LITERATURE

Camilla, Bloody Little Imbecile

Collected Poems

Dam-Burst of Dreams
Christopher Nolan, Pan, 1988. ISBN: 0330303171. Collected poems and other writings published in 1981 when Christopher Nolan was 15, and which he wrote using a ‘unicorn’ on his forehead to punch the keys of a typewriter.
Down all the Days, Christy Brown. Secker & Warburg, 1970. ISBN: 0436070901. Novel about a disabled boy in Dublin during the '40s and '50s, and written 13 years after 'My Left Foot'.


Under the Eye of the Clock: The Life Story of Christopher Nolan. Christopher Nolan. Phoenix paperback, 1999. ISBN: 0753807092. Christopher Nolan was born in Ireland, nearly dying at birth from asphyxiation, which caused his disability. 'Under the Eye of the Clock' is a powerful and moving autobiographical novel from a gifted writer with cerebral palsy who has been compared to Joyce, Yeats and Dylan Thomas. First published in 1987, 'Under the Eye of the Clock' is an international bestseller.

**YOUNG PEOPLE’S EXPERIENCES**

Between Ambition and Achievement


Easy for you to Say – Q&As for Teens Living with Chronic Illness or Disability

No Choice, No Chance – The Educational Experiences of Young People with Disabilities
Educable, 2000. ISBN: 1841470218. Research report exploring the choices that young disabled people have when it comes to education, and how these choices affect them when they leave school.

Taking Charge – Teenagers Talk about Life and Physical Disabilities

Whose Voice is it Anyway? Talking to Disabled Young People at School
Christine Wilson and Rowen Jade, Alliance for Inclusive Education, 1999. Report of a project aimed at empowering young disabled people, which includes interviews with them.

**GENERAL**

Mustn’t Grumble, Writing by Disabled Women

Pride Against Prejudice: Transforming Attitudes to Disability

Index for Inclusion*
1997 CSIE. Self-review tool for schools to find out how inclusive they are and monitor their progress towards greater inclusion.

Education Equality and Human Rights*

*Available from www.diseed.org.uk

If you know of any additional resources to add to this list or for further information, go to:
www.speakingforourselves.org.uk
call 020 7619 7228 or write to:
Speaking For Ourselves Scope Creative Services 6 Market Road London N7 9PW
Did you know that:

■ 38% of young disabled people have been bullied at secondary school?
■ one in three disabled people has been turned away from pubs, restaurants, theatres and leisure centres?
■ over a million disabled people wanting to work are denied the opportunity to earn a living?
■ It is time to listen to what the UK’s 10 million disabled people want: the same human and civil rights as everyone else.

Find out more at www.timetogetequal.org.uk

Scope

■ Scope is a national disability organisation whose focus is people with cerebral palsy.
■ Scope’s mission is to drive the change to make our society the first where disabled people achieve equality.

To find out more about Scope, please visit www.scope.org.uk

Download a student pack of information about Scope and cerebral palsy from www.scope.org.uk/information/students.shtml