

# **Manifesto for Inclusion**

**Written by disabled people**



## Article 1

**‘All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.’**

10<sup>TH</sup> December 1948

## Contents

---

	Page
Preface	3
Introduction	4
Human Rights	6
<b>Independent Living</b>	
Overview	8
Assessment	10
Direct Payments	11
Advocacy	12
Housing	13
Transport	16
Education	18
Employment & Training	20
Public Procurement	23
Benefits	24
Media Representation	25
<b>Access</b>	
Built Environment	27
Open Spaces	28
Information	29
<b>Social Policy and Health</b>	
The Commission for Equality & Human Rights	31
Social Work	33
Provision of Mobility Aids	35
Sexual Health	37
Genetic Screening	38
Assisted Dying	40
Do No Attempt Resuscitation (DNAR)	41
Acknowledgements	42
Footnotes	43

## Preface

---

**By Dr Ann Wilson, Convenor**

***Inclusion Scotland*** was founded in 2001 as a result of a call from the grassroots of the Disabled People's Movement for a new, national, disability-led, organisation that would give disabled people a voice.

Inclusion Scotland is run by disabled people with policy issues set and tackled by us. We have the experience of disability, so we are best placed to speak on issues of inclusion. The underpinning ethic of our organisation is the recognition of the Social Model of Disability<sup>[2]</sup> and the Philosophy of Independent Living<sup>[3]</sup>. In short, 'the belief that people are disabled by society's reaction to their impairments preventing their participation as equal citizens.'

We draw attention to the barriers that affect our everyday lives as disabled people and exclude us from the mainstream of society. We work in partnership with politicians, public and private bodies as well as policy and decision makers to find ways of eliminating these barriers.

The role of Inclusion Scotland is that of a vehicle to enable communication and consultation between disabled people in Scotland and the policy and decision makers.

**We strive to ensure that issues, which are important to disabled people, are addressed and redressed. We provide active platforms for discussion that promotes the inclusion of disabled people.**

All our work is guided by the principle of the Social Model<sup>[2]</sup> and we endeavour to promote its merits to others. It is fundamental to our movement that we move 'away from a focus on individual impairments...and towards removing barriers, revising social norms, policies, cultures and promoting a supportive and accessible environment'<sup>[4]</sup> where we can live independent and fulfilling lives.

We have learned a great deal in the last three years and look forward to continuing to build on the work that we have done. It is our aim to continue to enable the voice of disabled people to really be heard by the policy and decision makers at every level of society. We strive to ensure that disabled people can make a real contribution to the improvement of everyday life for everyone in Scotland.

**There are 9.8 million disabled adults in the UK (nearly 1 million in Scotland.)**

**Over 5.5 million disabled people are of working age, which represents 16% of the working population.**

## Introduction

---

**By Bill Campbell, Project Development Manager**

**This manifesto is unique because it has been written by disabled people, and their allies, and the resulting document reflects the thoughts of disabled people themselves.**

**This manifesto** is a call to politicians and policy and decision makers in both the public and private sectors of society to work in partnership with disabled people to establish mechanisms where we can address and redress the barriers that exclude us.

It is based on five main documents, which are referred to through the manifesto:

1. **The Universal Declaration of Human Rights**<sup>[1]</sup>
2. **The Social Model of Disability**<sup>[2]</sup>
3. **The Philosophy of Independent Living**<sup>[3]</sup>
4. **The Madrid Declaration**<sup>[4]</sup>
5. **The European Parliament of Disabled Peoples' Manifesto**<sup>[5]</sup>

This manifesto is a **'human rights based'** document. We are no longer prepared to ask for our rights in the hope that someone will listen. We have to move 'away from disabled people as objects of charity and towards disabled people as rights holders' who have an equal role to play in society.'<sup>[4]</sup>

**We acknowledge** that over the past ten years much legislation has been enacted in the United Kingdom designed to alleviate the social exclusion of disabled people. However, legislation in itself is only one element of the inclusion equation. Without proper enforcement procedures and a genuine willingness by public and private bodies to implement legislation, we are frustrated in our efforts to gain the all important **'human rights'** that others in society enjoy.

We recognise that proper, fulfilling employment with prospects for self achievement and advancement is the best form of social and economic welfare. Therefore, we support mechanisms that properly finance and resource inclusive education, lifelong learning, the training for, and provision of, **real jobs** that give disabled people dignity and self worth.

## Introduction

---

Therefore, we must move 'away from labelling disabled people as dependents or unemployable and towards an emphasis on ability and the provision of active support measures'<sup>[4]</sup> that will empower us to be net contributors to the economy.

We recognise that for some people, paid employment is not an option and that for others, a period of re-adjustment is inevitable. We must **stop** characterising people on benefits and allowances as scroungers living off the state and construct a system whereby people are supported financially while adjusting or re-adjusting to their place in the jobs market whilst, at the same time, ensuring that **no-one remains trapped in poverty**.

The writing of this 'Manifesto for Inclusion' can be viewed as a **natural** progression along the road towards full and meaningful inclusion within a society that, for too long, has failed to listen and take seriously the views of disabled people themselves. This Manifesto is a genuine attempt by disabled people in Scotland to become more engaged in the mainstream of society by drawing to the attention of policy and decision makers the issues that affect our own lives and deny us our **human right** to a rich, dignified and fulfilling life.

Although there is a long way to go before we solve the equation, which is the maxim of the Madrid Declaration, we hope this document will act as a catalyst to get us there :

**Non Discrimination + Positive Action = Social Inclusion<sup>[4]</sup>**

**We, the disabled people in Scotland, therefore call for all candidates standing for election in 2005 to commit to realising the demands that are outlined in this document.**

Allies such as families, friends, colleagues and assistants are also concerned that society should take the concerns of disabled people into account. Disability issues are issues for everyone<sup>[5]</sup>

The final report 'Improving the Life Chances of Disabled People' states that, by 2025, disabled people should have full opportunities and choices to improve their quality of life and be respected and included as equal members of society.<sup>[6]</sup>

## **Human Rights**

---

The human rights of all disabled people must be respected.

The European Convention on Human Rights, the United Nations Declaration of Human Rights and its Charter on the Rights of Disabled People all provide the framework for our demands for basic human rights.

**We call for:**

- **The right to live free from discrimination**
- **The right to freedom of speech**
- **The right to shelter and asylum**
- **The right to family and personal life**
- **The right to be well**
- **The right to equal treatment in all public services**
- **The right to education and learning in a school or college of our choice**
- **The right to a decent income through work or benefits**
- **The right to be safe on the streets and in our homes**
- **The right to live in the community, not in institutions**
- **The right to respect for our culture, religion and life choices**
- **The right to have a say in the decisions made about our lives**
- **The right to equal access to employment**
- **The right to equal access to information**
- **The promotion of the rights of disabled children and adults**
- **The tackling of disability discrimination, racism, sexism, homophobia, age-related and religious discrimination**
- **Action against prejudice and negative portrayals of mental health system users, asylum seekers and other marginalised groups**
- **Effective action against hate crime, including harassment and domestic violence against disabled people**
- **The promotion and recognition of British Sign Language and Alternative and Augmentative Communications Systems (AACs)**
- **Opposition to the Mental Capacity Bill and the Mental Health Bills, which threaten the human rights of people with learning difficulties and mental health system users**
- **The support of the Disabled People's Rights and Freedoms Charter**

# **Independent Living**

## Overview

---

**What is independent living:** Independent living simply means disabled people having the same choice, control and freedom over their lives as any other citizen – at home, work, in education and as members of the community at large.

**Why is independent living a rights issue:** Access to appropriate and adequate social support is fundamental to enable disabled people to participate fully in social and economic life. Lack of appropriate support can prevent people from exercising a wide range of basic human and civil rights: for example, the right to live in the community not in institutions; the right to family and personal life or the right to freedom of movement. Disabled people have very few rights to services that would guarantee assistance to enable independent living. What minimum provision there is does not guarantee very much more than being washed and fed.

**Institutionalisation:** There must be legal protection against disabled people being forced to live in institutional care against their wishes.

Supporting people to live in their own homes and enabling independence and participation are key elements to the government's objectives for modernising social services. However, overall social services provision is still weighted towards institutional care.

**Investing in independent living:** The balance of expenditure between institutional and non institutional care must be significantly transformed.

It is understandable that tax payers are concerned about demands on public expenditure and it is, of course, vitally important that proposals for extending independent living are economically sustainable. However, while the costs of support services are always closely scrutinised, relatively little attention is paid to the potential economic benefits of investing in independent living.

In reality, disabled people carry out numerous roles in society. The purpose of any form of support should, therefore, be to enable people to overcome the practical barriers they face in participating in all of these roles and activities, for example help with getting up in the morning to attend a meeting or go work. This is why expenditure on independent living needs to be seen as a form of positive investment. Increased participation not only benefits disabled people themselves but also produces economic benefits to governments, businesses and communities.

## Overview

---

**What changes are needed:** The current system for funding independent living depends on applying to a Government-sponsored charity (the Independent Living Fund). It also depends on local Community Care assessment procedures which vary from one local authority to another and which are subject to local funding policies, eligibility criteria and charging policies. Charitable and/or locally variable provision is no basis for ensuring human and civil rights. Support for independent living must be available as a right - with all disabled people who choose to do so being enabled to be in control of the support they need to live independently (i.e. with the support they need to pursue - on equal terms to non-disabled people - their lives in terms of education, leisure employment, parenting and family life).

A Task Force, set up by the Scottish Executive, similar to that in England, could develop the case for new civil rights legislation on independent living and to establish a properly funded and rights-based community care system, which would genuinely meet these rights.

Support for independent living must also be genuinely empowering - with services being judged by how well they support people to participate and contribute to their communities, and an increase in availability of services designed around people's convenience and within people's control.

Support for independent living must be integrated and easy to manage – ideally funded from a single, centralised source. This would enable people to move from one area to another more easily without having to re-negotiate a package of support. It would also avoid some people having to manage up to three or four sources of funding, each with its own separate administration system.

Finally, disabled people themselves are best placed to assist other disabled people in identifying and meeting their independent living support needs. Disabled people's own organisations must therefore be resourced and developed so that they can provide local, user-led information, advocacy, training and other independent living support services.

### **We call for:**

- **The right to live in the community with appropriate support and not in an institution**
- **A Scottish Executive Task Force to establish a right to independent living, to reform the social care budget and to review the options for creating a single, centralised source of funding for independent living**
- **Realistic support for local groups of disabled people**

## Assessment

---

Access to support for independent living usually depends on a Community Care Assessment carried out by a Social Work Care Manager. All too often, these assessments are driven more by existing services and budgets than by the real needs of the person concerned. Community Care Assessments should be a partnership, with the disabled person being recognised as the real expert on their needs and priorities and with independent advocacy available if required. Assessments and provision should be based on Best Value principles, taking full account of user-defined quality, not just cost<sup>[7]</sup>.

In the longer term the entire Community Care Assessment process should be reviewed and a system devised which makes the different interests of those involved in the assessment process more transparent and which distributes power more evenly.

Currently, unmet need is rarely adequately mapped in order to inform revised political and financial priorities for future service provision. We call for a systematic review to scope the real unmet needs of disabled people from a genuine independent living perspective.

At present local authorities are empowered to decide their own charging policies for people receiving community care services within certain broad guidelines. However, charging disabled people for services which they rely upon to achieve a basic degree of social inclusion is fundamentally unfair. Disabled people already incur considerable additional costs compared to non-disabled people<sup>[8]</sup>. Means-testing also effectively double-charges those who have already paid national and local taxes.

Support for independent living must be provided on an equitable basis – without prohibitive means-testing, which can prevent disabled people from gaining employment - increasing their disposable income and improving their quality of life.

### **We call for:**

- **A greater emphasis on self-assessment in the existing Community Care Assessment process**
- **A comprehensive review of the assessment process**
- **An end to charging for independent living support services**
- **An end to policies that penalise disabled people with high support needs and prevents them from working**

## Direct Payments

---

Direct Payments allow disabled people to purchase services to meet their community care needs instead of the local authority arranging services for them. This increases the choice and control people have over their lives. Direct Payments mean people can live in their own homes rather than in residential care, which improves the quality of their lives.

We welcome the commitment of the UK Government and the Scottish Parliament to increase social inclusion by introducing and promoting the implementation of Direct Payments legislation.

The take up of Direct Payments is low, particularly for those with learning difficulties and mental health service users, who are frequently discouraged from applying. Local authorities compound this by being unwilling to fund community care packages that cost more than residential care.

The way Direct Payments are implemented does not always maximise disabled people's choice and control unless they are underpinned by the Philosophy of Independent Living<sup>[3]</sup>.

The Social Work Duty of Care, as it is implemented at present, is often too restrictive and requires re-definition. It must genuinely promote social inclusion, choice, control and flexibility and maximise equal citizenship.

At present, disabled people encounter difficulty in retaining their agreed Direct Payments package if they move from one local authority to another. A previously agreed Direct Payment package should be retained.

It must be recognised that support services for people using Direct Payments are best run and controlled by service users themselves and sustainable funding should be given to these groups. There must also be adequate funding within Direct Payment packages to cover the administration costs of disabled people employing their own workers.

There must be changes in the ethos and practice of respite care to allow the creative use of Direct Payments to provide more flexible alternatives.

Direct Payments are potentially the most significant statutory measure in facilitating genuine independent living since The Social Work (Scotland) Act 1968<sup>[9]</sup> and The National Health Service and Community Care Act 1990<sup>[10]</sup>.

### **We call for:**

- **The 'Duty of Care' retained by Social Work to be re-defined**
- **The implementation of Direct Payments to be founded on Independent Living Principles**
- **The Ordinary Resident regulation to be reviewed**
- **Realistic funding for user led support services**

## Advocacy

---

The new Mental Health Care & Treatment (Scotland) Act 2003<sup>[11]</sup> states that any person with a mental health 'disorder' has a right to independent advocacy. The Act places a duty on health boards and local authorities to secure the availability (to persons in its area with a mental health disorder) of independent advocacy services and to take appropriate steps to ensure that those persons have the opportunity to make use of those services.

There are still gaps in independent advocacy provision for children & young people, older and disabled people. Perhaps the largest gap concerns 'hidden' groups such as homeless people, people with substance abuse problems, prison leavers and other marginalised individuals.

There is an imbalance in funding of advocacy provision in some areas between NHS boards and local authorities - this needs to be addressed. Commissioners should ensure that all advocacy organisations have robust and long-term Service Level Agreements.

Local planning partners need to consider how they involve and consult with people using services in a meaningful and transparent way. If service users are continually supported to express their views, and they are taken into account, this will go a long way towards the development of advocacy that is responsive to need.

### **We call for:**

- **All planning partners to develop advocacy services for all people with a mental health disorder to meet the requirements of the Mental Health Care and Treatment (Scotland) Act 2003**
- **More secure funding to place existing and new advocacy organisations on a sounder footing**
- **The development of an advocacy training strategy**

**“Advocacy is widely recognised as an important way of enabling and empowering people to make informed choices and to gain, and remain, in control of their own lives. It helps people to have access to the information they need, become aware of the options open to them and make their wishes known”.**

**“There are different types of advocacy. The Scottish Executive, through the Advocacy Safeguards Agency is promoting the development of Independent Advocacy. This means that advocacy projects/services, and their advocates, operate independently of other service providers. This removes any conflict of interest and enables an independent focus on the individual”**

Effective Interventions Unit, Scottish Executive 2004

## Housing

---



We believe that accessible housing should be considered as a basic human right. The lack of accessible and suitable housing is a major barrier preventing disabled people living independent lives with access to all the opportunities most non-disabled people take for granted. It can be impossible to take up employment, educational or social and recreational opportunities if you can't get in and out of your own

home or if the living environment is so difficult and hostile that it takes all your time and energy just to do the basics, like bathing, washing and eating.

With a population of approximately 830,000 disabled people in Scotland, the current figures for Barrier Free housing only totals 25,950 (this includes very sheltered, sheltered, medium dependency, wheelchair, ambulant disabled and other specially adapted housing.<sup>[12]</sup>)

There is one main area where the Human Rights Act 1998<sup>[13]</sup> has obvious implications for disabled people in housing need:

Article 8 – The Right to Respect for Private and Family Life: Everyone has the right to respect for their private and family life, their home and their correspondence.

Article 8 was recently used by a disabled woman in England to claim damages after being forced to live in a 'wholly unsuitable' home due to failures of the social services and housing departments.

Local authorities across Scotland have identified significant shortfalls of housing for disabled people. In Glasgow, for example, the local authority has identified a need for over 4,500 new Barrier Free and fully wheelchair accessible houses. This shortage must be addressed through the strategic planning and investment strategies.

Currently, Scotland's largest city, Glasgow, spends around £14 million pounds a year on equipment and adaptations; in some occasions this is just making unsuitable housing slightly less unsuitable.

Many 'Care & Repair' organisations in local authorities are also starved of adequate funding, each and every year, which in turn creates many difficulties for disabled people, their families and carers.

**The stock of larger, accessible or adaptable properties in the public and independent sectors has reduced as a result of the Right to Buy policy.<sup>[12]</sup>**

## Housing

---

This, for some disabled people, can mean 'imprisonment' within their own homes. Also, inadequate funding for Care & Repair, and for councils, can lead to more cases of 'delayed discharge' from our hospitals. In cases like this a few hundred pounds that can not be found by local authorities to put in necessary adaptations can mean that health boards are having to spend many more thousands of pounds to keep people in hospital settings unnecessarily.

It is true that there are slightly higher costs in the development of built-in accessibility but this would be quickly repaid by the reduction in the need for equipment and adaptations throughout the life of the property e.g. a stairlift can be £2,000 - £4,000 to fit retrospectively to a house or an extension to give a downstairs bathroom and bedroom can easily cost £40,000. Homes for Scotland (representing house builders) estimate the extra cost of building a Barrier Free house to be approximately £1,600 per unit.

We fully support the equality and mainstreaming agenda of The Scottish Executive but the most urgent need is for housing suitable for wheelchair users to live in and the need is for accommodation of all sizes not just smaller one / two bedroom properties. We would also call for accessible housing to include some really quiet, well sound-proofed housing.

All housing providers have to work within the planning and development criteria set by the local authority. They are therefore uniquely placed to ensure that the housing sector across all tenures (Registered Social Landlords and co-ops, private developers etc) take into account the needs of disadvantaged people and provide houses fit for all citizens.

Disabled people want and need housing to rent, but also to buy, local authorities, through their planning and development functions, should specify clearly the need to have equality of housing opportunity in the use of land.

Poor, inadequate or inappropriate housing can not only increase the impact of a person's impairment but also can be a direct cause of disability.

Housing should be affordable and should meet the cultural, social and access needs of all disabled people. All housing developments should have a minimum of ground floor housing designed and built to 'Barrier Free' standards. Letting agents should indicate clearly a property, which is Barrier Free or has adaptations.

10% of all properties built must be designed to enhanced 'fully wheelchair accessible' standards so that they have sufficient space in all key living areas.

## Housing

---

There is a requirement in the Housing Scotland Act (2001) calling for local authorities and housing providers to gather information on the numbers of disabled people requiring adapted housing and also the amount of available adapted / accessible properties and this requires implementation.

There should be a review of the way in which local authority housing lists are administered and how waiting list points are allocated, especially where medical conditions are taken into account.

Local authorities should make equity loans for house purchase available to disabled people in need of housing up to 25% - 50% of the value of a house, to be repaid when the property is sold.

The Scottish Executive must ensure that all new build and major renovation programmes include provision to meet the needs of disabled people living in Scotland both now and in the future.

All local authorities must be encouraged to pursue a policy of including representation from organisations of disabled people in their policy and planning processes to ensure their voices are heard and their needs are taken into account.

There should be an end to the policy operated by many councils, that sees adaptations to properties removed if a disabled person cannot be found to occupy the property. This is a waste of scant resources.

### **We call for:**

- **Varied and flexible housing across all tenures**
- **All houses in a development to have ground floors built to 'Barrier Free' standards**
- **The immediate implementation of information gathering by local authorities on the numbers of disabled people requiring adapted housing and the amount of such stock available**
- **Local authorities to provide equity loans to disabled people**
- **All local authorities to listen to disabled people when drawing up housing strategies**
- **An end to the removal of adaptations from housing while awaiting a disabled tenant**
- **A review of local authority housing lists**



It is unfortunate that many disabled people will not be able to use their travel cards until 2017 when all buses are expected to be fully accessible.

It is with disappointment that we note that bus companies will not be required to have complete 'low floor' bus fleets before 2020. It would be most welcome if bus companies and the Scottish Executive were to agree to introduce a national network of accessible buses well before this date.

In line with this argument, we ask for Government support and encouragement for rail companies to introduce accessible trains, together with the necessary adaptations to stations, as soon as possible. However, at the latest, this should happen by 2020, as per the recommendation in the Disability Discrimination Bill<sup>[14]</sup>.

Dial-a-Bus and other community transport schemes require review, especially in regard to timetables and their boundaries of operation. Many journeys (such as hospital visits) involve crossing local authority boundaries and, at present, community transport does not take this into account.

Assistance for disabled people getting on/off trains needs to be improved. There should be no need to book up hours or days in advance to get assistance as is the case for some disabled people at present. There should be a unified assistance policy for rail services throughout the United Kingdom so that disabled people can enjoy the same rights as non-disabled people regarding travel. There should also be a far more robust booking system where you would be able to phone, perhaps half an hour in advance, and say that you are planning to take the train. So that we can travel where we want, when we want.

There must be more discussion between the Scottish Executive, local authorities, the taxi trade and disabled people regarding any future legislation to do with accessible taxis. Such taxis are obviously better for disabled people who are wheelchair users but for some, who have an ambulatory impairment, these types of taxis may not be the best choice. We believe that more discussions should take place between all parties to reach an amicable agreement that is acceptable to all.

There is a need for a universal Taxi Card scheme, which would apply throughout Scotland.

Consideration must be given to increased financial support for public transport in rural areas with isolated populations, especially disabled people.

## Transport

---

Ferries are an integral part of life for people living on islands. Therefore, there is a pressing need for ferry operators to ensure that their vessels are fully accessible to disabled people.

We are living in a world where air travel is the norm rather than the exception. Mechanisms have to be found whereby disabled travellers can use both airports at either end of their journey and have full access to planes without incurring a surcharge. This has to be achieved by meaningful dialogue across the airline industry and enforceable regulations introduced at European and international levels.

The current system of integrated transport provision (where transport links are required) needs to be overhauled. Now that the First Bus Group have a substantial transport portfolio, both in buses and trains across Scotland, they need to ensure that transport continuity exists. People should be confident that when they make a journey they are able to complete it if they are using more than one link.

Attention should be given to the provision of 'quiet areas' in all public transport, airports, railway and bus stations.

At present there are only three airports in the UK that will accept the transport of assistance animals and none are in Scotland. The ability to transport assistance animals together with their owners must be extended to all carriers and airports.

### **We call for:**

- **Inclusion of stakeholders in the formulation of Transport Strategies and associated legislation at all levels**
- **A standardised assistance policy for all rail services throughout the United Kingdom**
- **A robust standardised assistance booking system for rail journeys**
- **Consultation with disabled people on accessible taxi legislation and a universal Taxi Card scheme**
- **The current system of integrated transport provision to be overhauled**

**The end dates for accessible buses for disabled passengers are as follows:**

**January 2015 all single-decker buses less than 7.5 tonnes**

**January 2016 all single-decker buses more than 7.5 tonnes**

**2017 all double-decker buses**

**January 2020 all single and double-decker coaches**



Inclusion and Inclusive Education are increasingly becoming buzzwords to which everyone subscribes. However, behind the rhetoric lies a struggle for human rights, which is by no means won.

Powerful policy statements have been adopted following pressure from human rights activists and the Disabled People's Movement across Europe.

We welcome the fact that in the UK, the Government has adopted the Salamanca Statement<sup>[16]</sup> which promotes inclusion within mainstream schools and colleges and it forms the cornerstone of our objectives.

There are strong educational as well as social and moral grounds for educating children with special educational needs, or with impairments, with their peers. This is an important part of building a fully inclusive society.

Trade unions and the voluntary sector in the UK are now committed to all children having the opportunity to go to an inclusive mainstream school or nursery. Yet there remains considerable confusion and resistance to the development of inclusion from professionals, many of whom work in the education system, not least those who work in segregated special schools and the parents of these children. Parents and professionals need to be well informed in order for them to fully understand the benefits, to society as a whole, of an inclusive education at all levels and lifelong learning.

The reality of the education system in Britain is exclusion for many children, including the children of campaigning parents, because schools often cannot cope. In some cases, children are left with colouring books for most of the day as the teachers do not know what to do with them and often the learning support staff are sent to do other tasks like filing. Learning support staff are treated as if they are general staff and hardly get to spend time with the children.

Learning-disabled children are labelled as having behaviour problems because teachers do not know how to deal with them. This can be attributed to the fact that teacher training does not currently include disability equality training.

**The standards in Scotland's Schools Act of 2000 and the Education (Disability Strategies and Pupil Educational Records Act) were both predicted on a presumption of mainstream schools on the stance that it was both a right and an educational good.**

## Education

---

We welcome the move to close 'special needs schools' with an end to separating children from their family and friends and sending them to institutions far from home. We would expect to see this initiative complete by 2010. Units will need to be set up within certain schools for the education of pupils who cannot adequately be educated in the mainstream classroom.

Deaf children should have the opportunity to continue to learn and use British Sign Language (BSL) at school – learning BSL should be looked on as a valued skill for all children. However, deaf children should also be given the opportunity for social interaction with other deaf children.

Education and Careers services also need training and awareness in raising the expectation of disabled students to believe that employment is **a right and a realistic option** on leaving school.

### We call for:

- **Increased resources to support mainstream educational opportunities for all disabled children and adults**
- **Balanced information to be given to children, young people and adults on choices available in education and lifelong learning**
- **Disability equality training be included in the Continuing Professional Development of all educators**
- **Disability equality training to be a core module in schools and every educational establishment**
- **Learning and use of British Sign Language in all schools**

**“Inclusion requires the involvement of parent’s and children’s views. It means changes in teacher training and support and the flexibility to make decisions that might mean the same needs being met differently in different situations. Local authorities must plan better and spend differently. It needs methods of accountability that better measures a child’s progress without the individual child or their school feeling they are competing on unlevelled playing fields.”**

Ewan Aitken, Cosla Education Spokesman

## Employment & Training

---



Access to and sustainability of employment of disadvantaged groups is a key concern of the Scottish Executive. It recently commissioned research to collate the current evidence base in relation to disabled people's access to, and participation in, the Scottish labour market.

The research shows that up to a fifth of the population of Scotland is affected by disability. Despite economic growth and general improvements in the health of the population, the number of people claiming disability-related benefits continues to increase, while the employment rate of disabled people remains low. Employment and equality legislation has only a modest impact on overall employment rates.

Disabled people are far less likely to have qualifications than non-disabled people and this clearly has a negative impact on their employment outcomes. When they are in employment, disabled people are far more likely to be employed in low level occupations and are therefore likely to have lower incomes than non-disabled people.

At present, there are a number of issues preventing disabled people from being able to apply for jobs, attend interviews and carry out employment. Access to the workplace should be considered throughout the working life of any disabled person.

There are often significant barriers in terms of the financial implications of employment for disabled people, particularly in relation to part-time workers and those who want to consider self-employment. The costs of impairment should be recognised by social policy initiatives and benefit entitlement guidelines, in order that disabled people are not disadvantaged by choosing employment. Consideration should be given to provide financial assistance to disabled entrepreneurs and would-be entrepreneurs.

Disabled people should be able to access professional training and should be given the same opportunities to advance their careers as any other person. Additionally, initiatives should be supported that encourage alternative ways of training, such as distance learning, online training and so on.

All training materials or training information should be available in accessible formats.

Training should be available as a direct means to accessing employment. Disabled people participating in training should expect a job at the end of it.

Closer links should be made between training providers and employers, leading to meaningful, open employment.

## Employment & Training

---

Training opportunities for disabled people should be more flexible and creative in order to tap into the existing skill base that we have.

Training providers should face more scrutiny in providing meaningful outcomes for disabled people.

Flexible working arrangements and home working should be considered as alternatives in order to encourage disabled applicants and to allow more disabled people to work. Furthermore, home working is a viable option for many disabled people and employers / statutory services should actively seek to investigate this as an option when analysing their employment arrangements.

Disabled people are often not given support from Disability Employment Advisers (DEAs) when they approach the Department of Work and Pensions (DWP) for advice. Indeed, there have been a significant number of occasions, which have been reported, where disabled people are being told that they are not suitable for employment or any support, based solely on the *perceived* ability of the individual and regardless of any qualifications.

Disabled people in employment, or seeking employment, are very often unaware of the support available to them through Access to Work (ATW.) ATW is not sufficiently promoted to enable disabled people to confidently seek, secure and remain in employment. A rough survey of around 30 disabled people now in employment said they knew nothing about ATW before taking up employment and only heard about ATW from their employer, who had experience of employing disabled people.

The main issues in the use of ATW services are:

- Lack of coherency across the UK and even within Scotland on how ATW support is assessed and re-assessed
- Levels of funding available
- High staff turn over
- Apparent lack of understanding of the barriers faced by disabled people in employment

Many disabled people find that ATW is itself a barrier to employment due to the levels of bureaucracy, causing long delays from first point of contact to support / equipment being in place. This means months of waiting before full take up of a job and an employer having to hold a job while ATW support is agreed and supplied.

## Employment & Training

---

The reliance on 'expert' opinion, rather than self-assessment, adds to these barriers. For example, recently a disabled woman waited 10 months for an Occupational Therapist (OT) to agree her assessment for an office chair, where the disabled woman was quite capable of assessing her own requirements. Similarly, another disabled person had to sign a disclaimer rather than wait months for an OT assessment to have a second, identical piece of equipment supplied for a second place of work.

For people requiring personal assistance support, there is little understanding of the benefits of Direct Payments and how these can mean increased independence for disabled people. Often disabled employees are pushed to utilise agency support, which is neither empowering nor cost effective and is service rather than needs-led support. For disabled people who succeed in receiving their ATW support as a Direct Payment, there is little guidance, training or support offered by ATW. ATW staff seem to have little knowledge of the issues involved in being a personal assistant employer.

### We call for:

- **A coherent strategy to meet the needs of disabled job seekers and employees**
- **Disabled people to receive appropriate support and encouragement from Disability Employment Advisers**
- **Disabled people to be provided with the support that is needed in order to carry out the profession or work of their choosing**
- **A living wage to be mandatory for all employees**
- **An end to the 'revolving door' system of training where there is no actual employment at the end of the scheme**
- **An adequate training allowance provided to unemployed, disabled people**
- **All Access to Work (ATW) staff to receive disability equality training and training in Direct Payments**
- **A review of ATW assessment procedures, led by disabled people who use ATW services**
- **An improved mechanism for self assessment and reassessment of ATW support**

**Only 50% of disabled people are in employment in comparison with 87% of non-disabled people of working age**

## Public Procurement

---

Public procurement policies relate to the procedures for the award of public supply, public service and public works contracts. Public procurement policies are of major economic importance since this type of transaction accounts for a large percentage of the Gross Domestic Product. Moreover, they have a determining effect on certain sectors: construction and public works; energy; telecommunications and heavy industry.

At a time when unemployment and social exclusion have re-emerged, we believe that the insertion of appropriate social provisions in public procurement legislation constitutes the best possible economic incentive to promote direct employment of those who are underemployed, such as disabled people, in the public and private sector.

The European Disability Forum held a successful public hearing at the European Parliament on the inclusion of anti-discrimination and social clauses in the new public procurement directives.

Key European Union decision-makers, legal experts, stakeholders from companies, trade unions and Non Governmental Organisations agreed on the importance of integrating the economic, environmental and social aspects, the three fundamental pillars of sustainable development, in European Union legislation.

### **We call for:**

- **All public bodies to ensure that companies making tenders have, and are implementing, proper Equal Opportunities Policies before granting contracts**
- **All public bodies to take into consideration the social aspects concerning disadvantaged and excluded groups when considering tenders for Public Procurement contracts**

**“For the first time, provisions on accessibility and employment of disabled people have been introduced into the European Union public procurement legislation. In particular, clearer rules for the use of social considerations, such as the possibility to employ a certain number of disabled people for the performance of a contract and a set-aside system for sheltered employment, and provisions for accessibility of works, supplies, and services for disabled people to be included in tendering documents, has been foreseen in the new text.”**

European Disability Forum, Public Procurement news

## Benefits

---

We believe that the current Incapacity Benefit system needs to be reformed. A recent report has found that the benefit, as it currently stands, has become a barrier to work. At the moment, in order to claim the benefit, individuals must demonstrate that they are incapable of work. Therefore, if they look for a job, they risk losing their benefit. Yet, at the same time, claimants are required to attend work-focussed interviews.

Incapacity Benefit, as it stands, is also inadequate as it fails to ensure a decent standard of living for people with a health problem or impairment who cannot work, as the average payment totals just over £4,200 a year.

There has to be reform of Welfare strategy in which Incapacity Benefit is replaced by a guaranteed income for those who cannot work and an enhanced allowance for those who are seeking some kind of paid employment. This should separate impairment and ill health from incapacity and could remove the incentive to move off Job Seekers Allowance and should also remove the incentive to remain on Incapacity Benefit to qualify for extra cash. Action agreements could be built into this reform. These could be negotiated between personal advisers, who would be well trained in the social model of disability and claimants. Agreed actions could include steps towards social and economic inclusion for those people who cannot work and actions to enhance employability through training and education for those for whom some kind of paid work is an option.

In short, it must be recognised that for some disabled people, paid employment is not an option and there must be a mechanism, which would remove people who are unable to work from Incapability Benefit and the accompanying obligation under the current system.

Disability Living Allowance should be enhanced to reflect the extra costs of living with a health problem or impairment.

### **We call for:**

- **A new active welfare reform strategy replacing the present Incapacity Benefit system**
- **A 'Disability Income' outwith the Benefits system**

**The Disability and Employment in Scotland Review of the Evidence Base 2004 shows that the top 20 areas in the United Kingdom where Incapacity Benefit claims are made are places that were previously the centres of heavy industry and coal mining.**

## Media Representation

---

It is without doubt, that the mass media has a significant impact on society and a major role to play in promoting an attitude shift, especially in the way society views disability. At present, the media under-represents disabled people.

Statistics on the employment of disabled people in the industry found that the number is generally very low. This is despite the fact that disabled people represent a vast audience. The media should focus on increasing the number of disabled people employed throughout the media industry, particularly at professional levels.

Disabled audiences are currently inadequately catered for and the media industry would almost certainly gain from addressing this issue more effectively. This should include increasing the coverage of the issues that specifically concern disabled people and their families.

It is vital that positive images of disabled people are promoted that are not based on charity or the medical approach and avoids negative stereotypes.

It should also be a priority to encourage close cooperation between disabled people and their representative organisations, the disability specific media and the mainstream media industry.

### **We call for:**

- **The promotion of change in the mainstream media sector to improve the portrayal and inclusion of disabled people**
- **Increased visibility of disabled people in all genres**
- **The creation of a fully accessible working environment in the media industry**

**“Media and advertising are one of the most powerful tools to change attitudes and mentalities in society, to overcome stereotypes, fear and prejudice. Therefore, by increasing and improving the image of disability in advertising, press, screen and air, media will actively contribute to an effective integration of disabled people in all fields of life.”**

European Congress on Media and Disability, Athens, 13-14 June 2003

# **Access**

## **Built Environment**

---

Government and all local authorities must ensure that the built environment is developed on the basic principles of the concept of **'Design for All'** together with appropriate law and planning policies as key elements of sustainable access provision.

In other words, what is required is that, those who are responsible for designing buildings or planning the external environment give due care and consideration to the needs of disabled people, as well as people with prams and older people, by implementing the philosophy of **'Design for All.'**

For many disabled people the negotiation of streets and buildings is an extremely threatening experience. Inappropriately placed street furniture and obstacles combined with inadequate signposting, reinforce a disabled persons' dependence on others and limits their capacity to participate freely in day to day life.

Street furniture: i.e. lamp-posts; telegraph poles; public seating; bus stops; shelters; traffic light poles; telephone kiosks; bollards; barriers; sign posts; electricity junction boxes; trees; advertising boards; etc can be used beneficially to provide directional guidance for people with, for instance, visual impairments but if they are incorrectly sited, they can create serious hazards. On a recent 'spot audit' of a 150-yard stretch of a High Street in the West of Scotland we counted over 200 such items.

### **We call for:**

- **Government, town planners and local authorities to consult with disabled people, and their organisations, when planning the layout of the built environment**
- **Heavy fines for traders and drivers who both litter the pavements with advertising boards and park their vehicles inappropriately**
- **Every local authority to employ a dedicated, suitably trained, full time access officer**

**"I have to confront the problems of the outside world that start as soon as I go through the back gate - kerbs too steep to mount, broken paving stones and the peculiar adverse camber of the pavement that threatens to tip me out of the chair or propel me into the road, something you never notice when just out walking.**

**The local highways department promises improvement, but not just yet - they are strapped for cash until the next financial year. Until then, the best they can do is mark the problem areas with yellow paint."**

**Ed Guiton, Guardian Newspaper columnist**

## Open Spaces

---

Many studies on health and well-being have indicated that physical, mental and spiritual health is greatly improved by exercise, particularly in Open Spaces.

Accessible outdoor spaces are places people can use and enjoy, regardless of background, age or economic status. Inclusive access to high quality public spaces is therefore a cornerstone of democracy and social equity. Inclusive access is at the forefront of good planning and design today and is central to government priorities in Scotland to improve people's quality of life.

Access for everyone to the Scottish countryside would greatly be enhanced if path providers and landowners recognised the needs of mobility and sensory impaired persons by looking at the following:

- Barrier Free or self closing gates for stock control
- Surfaces – firm, stable and slip-resistant
- Width, camber and gradient for wheelchair users
- Reliable, up-to-date information should extend to parking, public toilets, public transport accessibility and local ranger/landowner details

**We call for:**

- **Inclusive access for all to all public spaces**
- **Implementation of the Disability Discrimination Act (DDA) and Land Reform Act (Countryside Access Code) for access requirements by service providers, land managers and land owners**
- **An Access Officer in every area**
- **Improved access and signage to all public open spaces & parks**
- **Improved information on public open spaces & parks**

**“Social, cultural and governmental drivers call for greater engagement with all areas of the wider community in the delivery and enjoyment of public services. Inherent within this are National Parks which were arguably themselves established as part of the vanguard of social change.”**

Sean Prendergast, Head of Access & Recreation, Peak District National Park

**“There is increasing recognition that green spaces play an important role within society, not only in promoting health and wellbeing, but also in increasing social inclusion and community engagement with local natural environments.”**

Nina Morris & SG Cant, School of Geography, Plymouth

## Information

---

Disabled people have a right to information that is accurate, up-to-date, relevant and impartial. It also needs to be accessible to recipients. Information should be readily available in whatever format or language the recipient requests.

Information and advice centres must recognise disabled people's needs and aspirations. Services must enable users to make informed decisions. This applies to every type of information that someone may request – not just impairment-related subjects.

Service providers should take the following practical steps in order to meet the needs of disabled people:

- Produce all information in plain language and a minimum type size of 14 point
- Use a clear, easily recognisable, sans serif font. Use a matt paper of contrasting colour. Justify type on the left. Don't print sentences in block capitals
- On request, provide information in alternative formats such as large print, audio tape, Braille, and an easy-to-understand version
- Use interpreters for people who need to communicate in a sign language or other community language
- Websites should be designed and developed in a way which makes them accessible for disabled people
- Services should be provided in a flexible way, where appropriate using home visits, telephones, the internet or different opening hours
- Ensure that premises are fully accessible to people with mobility or sensory impairments
- Provide publicity materials which tell disabled people what a service can or cannot do
- Provide staff with disability equality training. A key barrier for disabled people is negative attitudes towards them
- Get regular and organised feedback from disabled people about the accessibility of the service
- Involve disabled people in service planning and training delivery

Information is not a luxury. It is an essential tool in all our lives. This is no less true for disabled people than it is for anyone else.

### **We call for:**

- **Disabled people to have the right to information in appropriate formats**
- **Disability equality training for all service providers**

# **Social Policy & Health**

## **The Commission for Equality & Human Rights**

---

The recent white paper on the proposed new Commission for Equality and Human Rights (CEHR) was made available for wide consultation in 2004. The document stresses the importance of the involvement of, and working with, the voluntary sector at all levels. To ensure meaningful grassroots input there must be adequate resources for local platforms of opinion and experience to feed into the CEHR.

The voluntary sector is very much the 'poor relation' of stakeholders when it comes to funding and this seriously impedes the sectors' ability to input its expertise and knowledge on a level playing field with other, better funded, stakeholders. If the government is serious in its intention of equal involvement of the voluntary sector, this needs to be addressed by direct funding of the voluntary sector.

It is proposed that a CEHR office is established in Scotland. The demographic nature of Scotland is such that thought needs to be given to ways in which the presence of the CEHR can be identified at local grassroots level. This should be a priority of the Scottish CEHR office.

It is proposed that there will be a CEHR presence in each of the nine English regions. However, it must be recognised that Scotland cannot be represented as a single 'region' and a CEHR presence will need to be established outside the central Glasgow – Edinburgh belt.

A single Scotland (and Wales) commissioner is insufficient to carry the workload expected and will lead to the marginalisation of Scottish (and Welsh) issues.

The new commission will have the ability to support individuals where multiple discrimination exists. However, there is grave concern at the lack of underpinning legislation for those strands not yet represented by commissions. This inequality will lead to great difficulty in pursuing cases where multiple discrimination exists with potential for injustice. There is an urgent need for an equalisation of legislation across the strands – a Single Equality Act.

There is concern over the provision of adequate resources for the CEHR. Its remit for the promotion of equality is much wider than those of the present single strand commissions. The white paper suggests that a single commission will be more cost effective than six single strand commissions plus a human rights commission. A single commission will, of necessity, need to look at equality and discrimination in its widest sense and will involve a different approach than that presently employed. New ways of working and guidelines will need to be researched and set up. There are vast funding implications involved in the organisation of a successful single equality and human rights commission.

## **The Commission for Equality & Human Rights**

---

Two concerns have been voiced universally:

1. There will be an inevitable hierarchy of strands based on the inequality of backing legislation
2. There is no clear guidance of where the funding for the commission will be sourced and the amount of funding envisaged

**We call for:**

- **The enactment of a Single Equality Bill as an urgent priority**
- **A clear statement of intent as to how the Commission will be funded**
- **The appointment of two Scotland (and Wales) commissioners**

**“Mainstreaming equality does not mean losing the focus on race equality or the specific concerns of women, those with disabilities etc. It means bringing that equality focus and perspective into the mainstreaming business activity of the organisation.”**

Jackie Baillie, Minister for Social Justice 2000

1. A 'client' was called to the office of her social worker for a review meeting. Her social worker, who was chairing the meeting, did not arrive. The meeting was postponed to be reconvened as soon as possible. The client is still waiting for the meeting **two years** later.
2. A care worker had been on all-night duty looking after a residential client. She came home and went to bed. Just two hours after her shift ended, she was awoken by a phone call to arrange further shifts.
3. A client with Aspergers Syndrome was being looked after by a care worker who had made it her business to learn about the condition and put in place a suitable care regime. A 19-year-old student who had no knowledge of the syndrome and did not read the guidance notes replaced this care worker.

Any organisation can make mistakes but these examples are, in fact, the norm in the current Social System. There is wide anecdotal evidence that Social Work Departments are chaotic and standards are rarely specified and seldom adhered to. Not only are clients inadequately supported but so also are staff members. This leads to poor morale and therefore a less than enthusiastic service.

The vast majority of disabled people come into contact with social services at some point in their lives. Social Service's remit does not stop there. It extends to older people, those temporarily incapacitated, children and families. It is, therefore, of vital importance that social work departments should be well organised with well laid-out systems of management and practice. This is certainly not the case at present.

Social Work departments are made up of a mix of various disciplines, all of which come into direct contact with the public:

- Social Workers
- Occupational Therapists
- Care Workers
- Managers
- Administrators

Social Workers and Occupational Therapists undergo recognised training to University standard. However managers, administrators and, in particular, care workers have no standard, laid-down, training requirement to enter into post. The amount of training received varies tremendously from one region to another – from reasonably good to very poor indeed.

## Social Work

---

It is care workers who have the most day-to-day contact with clients and it is their training and management that is most in question.

Anecdotal evidence suggests that many social workers and, in particular, care workers have little or no knowledge of the Philosophy of Independent Living<sup>[3]</sup> and the set-up and delivery of direct payment packages. There is inconsistency from one local authority to the next over what can or cannot be financed by a direct payments package. There is an urgent need for training of social work personnel in the concept of independent living supported by direct payment packages. It is vital that local authorities across Scotland should have a common policy for the delivery of Direct Payment packages.

Assessment of a disabled person in order to calculate the amount of funding given in a direct payment package is now carried out as a Single Shared Assessment between the Social Work and Health Departments. Unfortunately this innovative partnership working has resulted in many applicants being viewed from a medical model point of view. These assessors must receive adequate training in the Social Model approach.

### **We call for:**

- **A government review of the delivery of social care with particular attention to training at all levels**
- **This review should specify standardised management systems**
- **Training of Single Shared Assessors as a matter of urgency**
- **All training must include disability equality or diversity training**

**66% of disabled people are older people. In the next 50 years the number of over 60s will double and the number of over 80s will treble.**

## Provision of Mobility Aids

---

The service provision of wheelchairs in Scotland is completely inadequate and has deteriorated in recent years. Disabled people have to wait longer for assessments to be carried out and often they then have to wait unacceptable lengths of time to get equipment / chairs, which are then found to be unsuitable.

The provision of wheelchairs / power chairs is finance-driven instead of what equipment best suits the individual. It is not generally recognised that a wheelchair represents a person's 'legs'. Non-disabled people would not expect to walk around in inappropriate, ill-fitting footwear and a wheelchair user should not be expected to use the wrong type of chair. Assessors or Technical Officers (TOs) are not usually trained in disability equality and are, in the vast majority of cases, non-disabled people. Disabled people themselves are the best 'equipped' to gauge what type of wheelchair/power chair is best suited for them.

Non-disabled people are deciding policies about the future provision of wheelchairs. It would be more appropriate to establish partnership-working between wheelchair providers and wheelchair users with decision-making committees being largely composed of wheelchair users.

A review of maintenance services for wheelchairs must take place. There is a patchy, unreliable service at present and this also poses serious questions about out of hours provision.

Very often disabled people are having to use private companies to acquire wheelchairs/power chairs that are suitable to their needs because they are not receiving the right equipment via the NHS. This raises the question - is there a move by the NHS and the government to create more difficulties so that more disabled people are forced into buying their own equipment from the private sector? It has to be remembered many disabled people, who are already economically disadvantaged, cannot afford to go to private companies to acquire the right wheelchair/power chair. Also, when disabled people do buy their own chairs in this way, any repairs or services required to be carried out, have also to be paid for privately.

Often the NHS will not provide 'light-weight' wheelchairs, wrongly calling them 'sports chairs'. In some cases NHS officials say these types of chairs are unstable therefore they are classified as dangerous.

This, despite the fact that for many disabled people light-weight wheelchairs provide the best option. They are easier to push and easier to transport / lift in and out of a car and are more maneuverable. Providing wheelchairs that are too heavy for disabled people is like providing wooden clogs for non-disabled people to walk around in all day.

## **Provision of Mobility Aids**

---

Caring for a disabled child can be made easier with the use of certain aids, equipment / adaptations and for some families having the right equipment can also enhance their child's ability to become more independent and help ease the process of transition into adulthood.

However, items such as mobility aids or special beds are expensive and the range available is vast.

Parents and supporters insist urgent funding is needed to cut the long queues for assessment and equipment.

**We call for:**

- **A complete review of wheelchair/power chair services in Scotland**
- **The NHS to provide the best wheelchairs/power chairs suitable for a person's needs**
- **The decision making committees of those providing wheelchair services be made up, in the majority, of disabled people**
- **Further resources to be made available to families with disabled children**

**“All too often, environmental barriers limit the potential of disabled and older people to take part in mainstream employment, educational, social and recreational opportunities. Equipment and adaptations help to overcome these barriers, they can have a significant and positive impact on people's lives, and those of their carers, and can influence the need for other care services. They help people of all ages to carry out ordinary activities of daily life that have become difficult or impossible due to impairment, ill health, traumatic injury, the effects of ageing or a change in circumstances.”**

**‘Equipped for Inclusion’ Report of the Strategy Forum: Equipment and Adaptations**

**85% of disabled people in the UK were not born disabled but became so in later life through accident or illness.**

## Sexual Health

---

A recent Sexual Health Strategy document has been written for the delivery of sexual health services in Dumfries & Galloway, Scotland. This is an innovative document in that all marginalised groups, including disabled people, were involved in every stage of its production of the document. Each group proposed actions relevant to them.

It was acknowledged that disabled people often feel unable to seek advice about sexual health as they are seen as a section of society that 'doesn't have sex'. Young disabled people should be treated as equally as all other young people in the delivery of information and education about sexual health matters. No assumptions should be made about the ability of a person to wish to have a fulfilling sexual life. Their sexuality should be acknowledged and their emotional well-being addressed. Assumptions must not be made about the sexual orientation of a disabled person.

During consultation for the writing of the Dumfries & Galloway document disabled people identified that the most pressing need was for the setting up of a counselling service for disabled people. This service would need to be easily accessible and anonymous.

### **We call for:**

- **The acknowledgement of disabled people as sexual beings with attendant health and emotional needs**
- **The acknowledgement of disabled people as a group with particular needs in all sexual health documents**

**The Sexual Health Strategy 2003, Dumfries and Galloway document says that physically impaired people should have easy access to face to face and other forms of sexual health counselling, where possible with a physically impaired counsellor.**

## Genetic Screening

---



It is through our genes that we inherit characteristics from our parents. It has become recognised that the likelihood of developing many medical conditions is written in our genes and a few rare conditions are directly and inevitably passed on in our genetic code.

Genes are found on chromosomes – like beads on a string. Chromosomes are found in the nucleus of cells and - in women - in bodies called mitochondria floating in the plasma of cells.

Much work has been done on mapping where the genes responsible for human characteristics, including diseases, are found on the chromosome and in the mitochondria.

The Human Fertilisation and Embryology Authority (HFEA) is the regulatory body in this country, which will assess the clinical, moral and ethical implications of any proposed procedure involving manipulation of genes. This manipulation may be:

- Identification of an embryo with a gene likely to cause a medical impairment and offer termination of that pregnancy.
- Identification of an egg containing only ‘healthy’ genes and implant it in uterus.
- Remove the nucleus from an egg with mitochondria containing an ‘unhealthy’ gene and re-implant in an egg containing ‘healthy’ mitochondria from which the original nucleus has been removed. This procedure means that the resulting child will, in fact, have three biological parents.

Many disabled people are concerned that research and media reportage in the field of gene manipulation is leading to the expectation that we should look to a future when there are no disabled people. This, in spite of the fact that the vast majority of impairments are acquired **at or after birth** and are not the result of direct genetic inheritance. We are being led down the route of seeing disabled people as ‘mistakes’ that should not have happened. This is directly against avowed government policy of valuing diversity within our society.

## Genetic Screening

---

There are, however, a very small number of cases where gene manipulation could be seen as justifiable. It is the job of the HFEA to decide when such a procedure should be allowed. To ensure that the HFEA has an objective and independent view, the HFE Act requires that the Chair, Deputy Chair and at least half of the HFEA Members are neither doctors nor scientists involved in human embryo research or providing infertility treatment.

This regulatory authority has 21 members drawn from a wide spectrum of society. In reality important decisions are being made by as few as three members.

### **We call on:**

- **The government to review the HFEA to ensure increased openness and transparency with decisions being made after much wider consultation**
- **The authority to have representatives from the disabled people's movement among its membership**

**By the year 2010, 40% of the UK population will be over 45 – the age at which the incidence of disability begins to increase significantly.**

## Assisted Dying

---

Although a Scottish Executive spokesperson said that Ministers had no plans to change the present law surrounding issues of euthanasia and assisted dying, Jeremy Purvis MSP proposed to introduce an Assisted Dying Bill for debate in the Scottish Parliament. This is a devolved issue thus it is doubly important that disabled people in Scotland make their feelings known on this subject of great importance and concern to them.

The Disability Rights Commission (DRC) opposed Lord Joffe's Patient (Assisted Dying) Bill when giving evidence to the Select Committee in September 2004. They said, "However we believe that in the current climate of discrimination against disabled people, and where lack of access to palliative care and social support means that free choice does not exist, the threat to the lives of disabled people posed by such legislation is real and significant"<sup>[16]</sup>.

"The DRC believes it is essential to improve palliative care, and make it equally accessible across the country, before assisted dying is offered to patients. This is in line with the July 2004 House of Common's Health Committee report on palliative care recommendations, the 1994 conclusions of the Select Committee on Medical Ethics and World Health Organisation (WHO) recommendations. WHO recommend that governments demonstrate availability and practice of palliative care before considering assisted suicide / euthanasia."

"...The threat to disabled people remains too real and significant, especially given the current inadequacies in palliative care, and the inequality, prejudices and discrimination faced by disabled people in society through assumptions of quality of life and standards of living. This would especially affect those newly diagnosed with terminal illnesses."

We support this view, as expressed by the DRC. The Disability Movement has fought for the right to be recognised as equal citizens with equal rights and responsibilities. Government policy is only now beginning to take cognisance of this. The presence of legalised assisted dying will once more place disabled people into the ghetto of second-class citizens who should 'do their civic duty and request help to end their useless lives.' The action of a humane civilised society would be to support the concept of **assisted living** before turning its attention to assisted dying.

**We call for:**

- **All MPs and MSPs to vigorously campaign and vote against any move to alter the law as it stands at present on assisted dying**

## **Do Not Attempt Resuscitation (DNAR)**

---

Recent research focussed on Do Not Attempt Resuscitation (DNAR) notices has found that, while policies have been revised by nearly all Scottish health boards, consultants and doctors are still required to be better informed.

The research discovered that decisions about DNAR are still often based significantly on the individual consultant's views of the potential quality of life of a disabled person after cardiopulmonary resuscitation (CPR.)

There is also a great deal of disparity between the health boards, where in some cases a lot of resources have been put into this area and in others they are almost using a formula, rather than dealing with the issues.

Despite an emphasis on the importance of productive consultation with patients, awareness of disabled patient's right to advocacy from an independent go-between, who can convey their wishes to doctors, is limited. In some cases, DNAR notices have been found attached to patient's beds without consultation.

A lack of resources, however, means that many people find advocacy services are not available to them on the ground when they need them. If these services were freely available, the knock on effect could include a reduction in the number of court cases.

### **We call for:**

- **Increased awareness, and funding, of disabled patient's independent advocacy services**
- **Disability equality training and understanding of the Social Model to be a core module in training of all medical staff**

**“There is a need for greater support for disabled people and their families so their wishes can be communicated.”**

Sheila Riddell, Professor of Equality and Diversity at Moray House School of Education in Edinburgh.

**“A lot of research suggests that there are often preconceived ideas about poor quality of life and that is used to judge against disabled people.”**

Professor Nick Watson, Director of Glasgow University's Centre for Disability Research

## Acknowledgements

---

The writing of this manifesto has been an exciting and empowering exercise. It has brought together the views and experiences of disabled people from all over Scotland and further afield. This is very much our own document. Much burning of midnight oil has gone into its production by many people and their supporters.

Given the amount of support that we have received, over the last three months, in compiling this manifesto, it would be almost impossible to acknowledge the good work of everyone individually.

Suffice it to say, that we are extremely grateful for the contribution that each individual has made in giving us their thoughts and recommendations at our forums, on the telephone, by letter and e-mail or by passing on the results of discussions at meetings of their own organisations.

We would like to give a special acknowledgement to the staff of Inclusion Scotland for all the hard work that they have put into both facilitating and collating the input from various organisations and individuals.

## Footnotes

---

- 1.** The Universal Declaration of Human Rights:  
[www.un.org/Overview/rights](http://www.un.org/Overview/rights)
- 2.** The Social Model of Disability: [www.bcodp.org.uk/about/research](http://www.bcodp.org.uk/about/research)
- 3.** The Philosophy of Independent Living:  
[www.independentliving.org/docs6/hasler2003](http://www.independentliving.org/docs6/hasler2003)
- 4.** The Madrid Declaration: [www.madriddeclaration.org](http://www.madriddeclaration.org)
- 5.** The European Parliament of Disabled Peoples' Manifesto:  
[www.edf-feph.org/EPDP2003/about\\_en.htm](http://www.edf-feph.org/EPDP2003/about_en.htm)
- 6.** Improving the Life Chances of Disabled People:  
[www.strategy.gov.uk/output/Page5046.asp](http://www.strategy.gov.uk/output/Page5046.asp)
- 7.** Stone, V., Quality and Disability – Equality In the Best Value Regime, Disability Rights Commission, 2001:  
[www.drc-gb.org/publicationsandreports/publicationdetails](http://www.drc-gb.org/publicationsandreports/publicationdetails)
- 8.** Smith, N. et al, Disabled people's costs of living: 'More than you would think', Joseph Rowntree Foundation, York, 2004:  
[www.jrf.org.uk/knowledge/findings/socialpolicy/054.asp](http://www.jrf.org.uk/knowledge/findings/socialpolicy/054.asp)
- 9.** The Social Work (Scotland) Act 1968:  
[www.scotland.gov.uk/library5/social/dpswsa-00.asp](http://www.scotland.gov.uk/library5/social/dpswsa-00.asp)
- 10.** The National Health Service and Community Care Act 1990 -  
[www.legislation.hmso.gov.uk/acts/acts1990/Ukpga\\_19900019\\_en\\_1](http://www.legislation.hmso.gov.uk/acts/acts1990/Ukpga_19900019_en_1)
- 11.** Mental Health (Care & Treatment) (Scotland) Act 2003  
[www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003](http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003)
- 12.** Statistical Bulletin HSG/2004/4: Housing Trends in Scotland: quarters ending 31 December 2003 and 31 March 2004 -  
[www.scotland.gov.uk/stats/bulletins/00357-00.asp](http://www.scotland.gov.uk/stats/bulletins/00357-00.asp)
- 13.** Human Rights Act 1998: [www.hmso.gov.uk/acts/acts1998/19980042](http://www.hmso.gov.uk/acts/acts1998/19980042)
- 14.** Draft Disability Discrimination Bill:  
[www.hmso.gov.uk/acts/acts1998/19980042](http://www.hmso.gov.uk/acts/acts1998/19980042)
- 15.** The Salamanca Statement of the UNESCO World Conference On Special Needs Education: Access and Quality (June 1994) -  
[www.diseed.org.uk/Salamanca%20Statement.htm](http://www.diseed.org.uk/Salamanca%20Statement.htm)
- 16.** An Executive summary of the Select Committee Evidence on the Assisted Dying (for the Terminally Ill) Bill September 2004 -  
[www.drc-gb.org/publicationsandreports/campaigndetails.asp](http://www.drc-gb.org/publicationsandreports/campaigndetails.asp)





# **Inclusion Scotland**

Find out more about Inclusion Scotland

Tel: **0141 887 7058**

Fax: **0141 848 7551**

E-mail: **info@inclusionsscotland.org**

Or visit our website at: **www.inclusionsscotland.org**

To Inclusion Scotland's knowledge, all information contained in this  
Manifesto is correct at the time of print.