Disability Rights Commission

Research

Disability in Scotland 2005–2020
A State of the Nation Report

Scottish Council Foundation

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independent thinking

Making rights a reality

The Disability Rights Commission

The Disability Rights Commission (DRC) is an independent body, set up by an Act of Parliament, which has the goal of creating a society where disabled people and those with long-term health conditions can participate fully as equal citizens.

We work with the voluntary sector, the business community, government and public sector agencies to achieve practical solutions which benefit disabled people and society as a whole.

There are around 10 million people with rights under the Disability Discrimination Act in Great Britain. The legal definition of disability covers people with physical, sensory, communication and intellectual impairments, and people with mental health and other long-term health conditions such as diabetes, epilepsy, cancer, multiple sclerosis, HIV and schizophrenia.

Under the Disability Discrimination Act 1995, disabled people have the legal right to fair treatment in employment, in education and as customers of services. Most duties of the Act are now in force. A new Disability Discrimination Act received royal assent in 2005. This will create a duty on public bodies to actively promote disability equality from December 2006 as well as close some of the loopholes in the previous Act.

The DRC has offices in England, Scotland and Wales and can support both those with rights and those with responsibilities under disability legislation. For further details of how we can help you please contact our Helpline – contact details can be found on the back cover.

In 2007, a new Commission for Equality and Human Rights will begin its work. This body will have responsibility for the activity currently undertaken by the DRC.

To obtain a copy of this report or an alternative format please email:
scotland@drc-gb.org

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Executive Summary

> Encouraging equal opportunities does not always mean treating people the same. It can also mean considering and reflecting difference. (Scottish Executive, 2000b)

Introduction

The Disability Rights Commission (DRC) commissioned this study from the Scottish Council Foundation. The aim was to bring together information from existing sources that illuminates the position of disabled people in Scotland today and how it might be improved in the future. We hope that this information can be used to support our vision of a society where all disabled people can participate fully as equal citizens.

The study focuses on:

- how policy, attitudes and awareness in relation to disability have to change to enable disabled people to participate as equal citizens, and
- how future demographic changes might impact on disabled people.

What the study involved

The study comprised 'desk' research on key themes, using the Internet, research by Disability Rights Commission and published papers. It began by looking at the attitudes of disabled people and others towards disabled people and their identity. It then explored a number of themes: communities; housing; transport; access to goods and services; health, wellbeing and independent living; education and learning; work and worklessness; and income and living standards. Each of these themes covers a range of support mechanisms or services that disabled people access during their lifetime, and for which Scotland has mainly devolved responsibilities and is thus able to determine its own agenda. The study also included a review of future demographics.

The research aimed to establish how the experiences of disabled people compared with the Scottish population as a whole. The aim was to identify similarities and differences, and where possible to identify the root cause of different experiences. The study tried to answer these questions by exploring participation, experience and outcomes of disabled people in relation to key themes that impact on quality of life.

The study analysed recent statistics and considered statistical trends to establish as far as possible the current position of disabled people in Scotland, and to develop an estimate of the potential number of disabled people in Scotland by 2021.

The study drew on ideas from the social model of disability. This locates disability in the material, social and attitudinal barriers faced by disabled people, rather than on an individual's impairment.

Conclusions

On the surface, attitudes Scots express about disabled people are almost uniformly positive. Many do not believe that disabled people are treated fairly in society. Attitudinal barriers, or the negative stereotypes within society that are commonly attached to disability, still exist. These are often the hardest barriers to overcome: however, changing attitudes can be very important to improving the lives of disabled people.

Disabled people do not fare as well as non-disabled people in their experience and outcomes from mainstream public services, such as healthcare, housing, education and social care. Our research has concluded that progress has been made in Scotland in recent years – through legislation, policy and initiatives – in raising employment levels, improving access to learning, and increasing the accessibility of public transport. However, disabled people still face numerous barriers in realising equal opportunities, environmental and access barriers, and legal and institutional barriers. This can result in discrimination and social exclusion.

Many disabled people live in deprived communities, and will suffer disproportionately from the poor provision by both commercial markets and public services in such areas. They also have limited choices to improve their outcomes by moving to a better area or using their purchasing power to achieve better services. Equalising life chances should mean equalising access and outcomes for disabled people compared with the wider population. This would require unjustified inequalities being removed, and spreading the risks, for example of poverty and unemployment, more evenly across the whole population.

Poverty is both a cause and a consequence of disability and exclusion. There is a multi-dimensional and dynamic nature to the types of poverty disabled people can face. They are more likely to be out of work and dependent on benefits, while at the same time they often experience higher living costs than non-disabled people. They are less likely than others in society to be in a position to accumulate assets over the course of their life. Disabled people are also likely to suffer from poverty of ambition as a result of their experiences, and from a poverty of social networks because of physical or attitudinal barriers and a lack of confidence that stops them participating in activities in the community and wider society.

While there is general agreement that ‘things are getting better’, the challenges involved in tackling years of inequality are immense. Many of the defining features of an equal society are missing for disabled people. For example, choice, autonomy, opportunities to learn and to work, and appropriate social and economic support systems are all more limited for disabled people than for the wider population.

Equal citizenship is unlikely to be achieved unless the rights and needs of disabled people are recognised and appropriate responses put in place. This does not mean simply treating disabled people the same as everyone else, but providing ways – ways that are appropriate and as personalised as possible – to take account of their different needs, experiences and impairments, to ensure disabled people attain equal access and outcomes. This type of approach would be an effective start to 'closing the opportunity gap' which exists within Scotland.

Recommendations

Tackling the inequalities experienced by disabled people can make a difference to their lives, but only if this results in consistent, inclusive and equal outcomes. This poses a number of challenges to both public policy and wider society that can only be overcome with imaginative and creative responses – more of the same will not do.

Focus on needs, not disability

There is a need to redress the persistent inequalities in participation, experience and outcomes for disabled people, while at the same time accommodating the diverse needs of those described as disabled people. Categorisation according to needs rather than disability would offer a truer indication of reality, reflecting the changing needs people have during the course of their life, and would fit with changes in policy and practice which organise delivery around stages of people's lives. This would result in a more 'socially just' mix of public services and support.

Some practical actions include:

- treating disabled people in a way that takes account of their different needs may mean disabled people are treated more favourably than other people in society if they need additional resources to achieve the same outcomes
- equality does not mean taking steps explicitly to 'correct' any perceived imbalance towards disabled people, but ensuring they are an integral part of policy thinking and practice. Good design and delivery benefits everyone in society.

Disability and multiple disadvantage reinforce the need for greater choice and more personalised responses by public and private service providers. This would benefit not just those with disabilities but the wider Scottish population.

Some practical actions include:

- providing services based on need, not impairments, building on principles of personalisation, choice and equality
- improving communication between support organisations
- providing choice through a diversity of provision and providers and an effectively resourced support infrastructure.

Community involvement

Community involvement is important because it can build, strengthen and maintain social networks, and can help in identifying priorities for investment in the infrastructure of the community. In planning 15–20 years ahead, there are practical challenges in building communities that have the best possible social and physical infrastructure, and improving the quality of services to support the needs of all residents, particularly those with an impairment.

Some practical actions include:

- increasing the number of accessible buses, taxis and parking spaces in local areas
- including disabled people in decisions affecting their local community, through community planning, community councils or other local groups
- increasing the use of alternative formats to communicate useful information to residents.

Employment

Persistently low employment rates for disabled people at a time of general economic stability and growth in jobs are bad for the whole economy and society, not just for disabled people themselves. Tackling restricted access to jobs for disabled people, particularly those with fluctuating mental health problems, is a huge agenda but one that requires to be tackled with sensitivity and greater urgency.

Some practical actions include:

- improving the employment rate of disabled people through raising employers' and employees' expectations of what disabled people can offer
- identifying 'what works' in initiatives such as New Deal or Pathways to Work and extending opportunities more widely to improve employment opportunities for disabled people
- creating more personalised working patterns by increasing the number of workplaces where flexible working options are truly available, accessible and attractive
- identifying ways to not only support disabled people into employment but also enable them to stay and progress within the workplace.

Income

There is a clear relationship between low income and disability, among both adults and children. In addition, disabled people and their families tend to have lower than average incomes, as well as above average living costs. One major issue for disabled people living in poverty is gaining access to an adequate income, through earnings, benefits and savings. Tackling poverty could have a major impact on the quality of life and wellbeing for many people who are currently, or at risk of being, disabled.

Some practical actions include:

- introducing a simple form of 'Saving Gateway' (the Government's new saving scheme being tested in parts of England; see HM Treasury/Department for Education and Skills, undated leaflet) for disabled people on low incomes

- providing explicit support for disabled people within the Scottish Executive's approach to financial inclusion
- increasing the number of social housing providers that offer 'insure with rent' options, where tenants can take out comprehensive home insurance for as little as £1.20 per week.

Healthy ageing

There is a clear correlation between ageing and disability. In Scotland the number of older people is expected to increase over the next 20 years. While life expectancy has risen by almost 10 years on average in the past 50 years, 'quality of life' expectancy has risen by about four years over the same period. A key policy challenge for the future will be to improve health and wellbeing over the course of life, by creating the conditions that promote and encourage healthy ageing.

Some practical actions include:

- improving work/life balance opportunities through flexible working arrangements for all. This could result in healthier, active older people choosing to continue in some form of paid work into their sixties
- balancing healthcare services, particularly long-term care and informal care, with approaches to help older people live self-sufficient and meaningful lives.

Positive attitudes to diversity

Changing the attitudes of individuals and society to place a higher value on diversity would help counter behaviours and attitudes that cause disabling conditions in society.

Some practical actions include:

- increasing opportunities for disabled and non-disabled people to come together and share experiences in everyday settings such as workplaces, learning centres, social spaces

- changing the language in use, to reflect that individual people are not necessarily 'disabled' in themselves: rather, disability can result from social barriers that hinder participation.

Individuality and differences exist within the population described as disabled, in the same way as they exist within the wider population. Rather than redressing 'deficits' that are perceived to result from disability, an 'asset'-based approach would focus on the contribution that disabled people can and do make to society.

Hearing the views of disabled people

Successful outcomes for individuals ultimately depend on their involvement in the design and delivery of services. If disabled people are involved in developing services, those services will reflect their priorities and aspirations. There is growing interest among policy-makers in Scotland and the UK in gaining a deeper understanding of the public's views, particularly on areas that directly affect their daily lives. This could provide a platform for the views of disabled people to be heard.

Some practical actions include:

- promoting opportunities to become involved at neighbourhood, local authority and national level would encourage active citizenship for disabled people
- involvement in policy- and decision-making processes offers a way for disabled people to shape services that are responsive to their needs
- encouraging citizens' panels or forums to actively recruit disabled people would enhance the range and diversity of membership.

'Out-of-work incomes'

Finally, we would propose setting up an enquiry to address the challenge of 'out-of-work incomes'. This is an area that has so far failed to receive the attention it deserves. The focus to date, although worthy, has been on redistributive measures to help pensioners and children. Non-pensioner single people and couples without children have to some extent been excluded. Welfare to work has improved the lives of many families on low incomes. However, there will be some disabled people (and other groups) for whom work is not an option. There are also people who are willing to work, but who face huge barriers in finding employment and can be out of work and suffer enduring poverty.

Introduction

The Scottish Council Foundation has undertaken this research on behalf of the Disability Rights Commission (DRC). The study is designed to support the Disability Rights Commission's vision of a society where all disabled people can participate fully as equal citizens. It focuses on:

- how policy, attitudes and awareness in relation to disability have to change to enable disabled people to participate as equal citizens, and
- how future demographic changes might impact on disabled people.

Our findings will also inform the Commission's submission to the Equal Opportunities Committee's Disability Inquiry.

To produce this report, we carried out 'desk research' on key themes, using the Internet, research by Disability Rights Commission and published papers.

We began by looking at the attitudes of disabled people and others towards disabled people and their identity. Attitudes are important because they influence how others in society perceive and treat disabled people. They can hinder or support disabled people's ability to participate as empowered citizens. Disabled people's perceptions about themselves, and how they define themselves, are based on their experience and are important features of how they interact with others in society.

The remaining themes of the study were chosen because they are essentially support mechanisms or services that disabled people will access during their lifetime, and they fall mainly within 'devolved responsibilities' for which Scotland can determine its own agenda. The themes are: communities; housing; transport; access to goods and services; health, wellbeing and independent living; education and learning; work and worklessness; and income and living standards.

We allocated each of these themes to team members within the Scottish Council Foundation who have knowledge and experience of the subject. The focus of the research was to find out about the experiences of disabled people compared with the Scottish population as a whole. The aim was to identify similarities and differences, and where possible to identify the root cause of different experiences. We tried to answer these questions by exploring participation, experience and outcomes of disabled people in relation to key themes that impact on quality of life.

We analysed recent statistics and considered statistical trends, to establish as far as possible the current position of disabled people in Scotland, and to develop an estimate of the potential number of disabled people in Scotland by 2021.

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1 Disability in Scotland: An Overview

1.1 What is disability?

Disability is difficult to define because it is a multi-dimensional concept and is far more than an individual health or medical problem. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of the socio-economic, cultural and political disadvantages resulting from an individual's exclusion.

The Disability Discrimination Act 1995 defines disability as: 'A physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities'.

Disabilities may be more prevalent than most people think. Much depends on how people understand the term 'disability' and how people choose to define themselves within that context. People can also be influenced by pride, embarrassment, public opinion and fear of discrimination when asked if they would define themselves as disabled. Additionally, people may have been born with a disability, acquired a disability as a result of accident or injury, or acquired a disability as a result of ageing. There are also different experiences associated with disability. For example, some disabilities are enduring but stable over a long period of time; others are progressive over time; and some are fluctuating (such as some mental health problems), making it difficult for the disabled person to experience consistency over their lifetime.

1.2 How many disabled people are there in Scotland?

In trying to estimate the number of disabled people in Scotland it is important to bear in mind that:

> There is no single or gold standard measure or estimate of disability. Variations in estimates of disability may be caused by a number of factors. These include variations in what is being measured, who is being measured and how disability is measured. (Tibble, 2004)

Different estimates of the disabled population are collated for different definitions of disability, making it impossible to go to a definitive source to estimate the number of disabled people in Scotland.

The main surveys are the Scottish Household Survey, the Labour Force Survey and the Census. They all rely on self-definition of disability, and use different wording to question and identify those people who would define themselves as disabled (Scottish Executive, 2004c). For example, the 2001 Census asked: 'Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do? (Include problems which are due to old age)'. The Labour Force Survey asks all working-age respondents: 'Do you have any health problems or disabilities that you expect will last for more than a year?'. If they answer 'Yes' to this question, they are also asked what kind(s) of health problem or disability they have, based on a list read to them by the interviewer. The Scottish Household Survey seeks information on disability in two separate parts of the survey: questions are asked of the highest income householder about all members of the household (including dependent children), and a random adult in the household is also asked about their own experience of disability and ill health. Results from the Scottish Household Survey highlight differences in perception of whether a 'health issue' is a disability/long-term illness or not (Scottish Executive, 2004c).

We have used a number of sources to build up a picture of the number of disabled people in Scotland. Readers should bear in mind the definitions employed in each case.

Some tables and data contained in this report define disability as a limiting long-term illness (LLTI), which means an illness, disability or infirmity that is longstanding (that is, it has troubled someone over a period of time or is likely to) and limits their daily activity or the work that they can do. Data from the Scottish Household Survey are collated and presented separately for those with a disability and those with a long-term illness so that the different characteristics of the disabled and long-term ill population can be highlighted. It has not always been possible to separately identify the disabled and the long-term ill population when using other data sources.

In an attempt to achieve some kind of consistency, there is at the time of writing a consultation on what questions relating to disability should be included in the 2011 Census. A series of questions is being tested in the 2006 Census trial. This may signal the start of a move away from a health or medical view of disability – where people are identified by their impairment – towards a view that disability is created by social attitudes towards people with impairments: that is, a social model – where people are disabled by the way society treats them differently from others.

Table 1.1: Adults with a disability or long-term illness by sex and age, 2001–02 (column percentages)

	No disability or illness	Disability	Long-term illness	Both disability and long-term illness
Men	82	7	7	4
Women	81	7	8	4
16–24	96	2	2	0
25–34	94	2	3	1
35–44	91	4	4	2
45–59	81	6	8	4
60–74	68	11	14	7
75+	55	19	18	9
Total	81	7	8	4

Source: Scottish Executive (2003d)

The 2001–02 Scottish Household Survey estimates that just under one in five adults in Scotland has a disability and/or a long-term illness (Scottish Executive, 2004c). Table 1.1 also shows that 18 per cent of men and 19 per cent of women consider themselves to have a disability and/or a long-term illness. Older adults are significantly more likely to have a disability than those in younger age groups: 45 per cent of adults aged 75 and over reported having a disability and/or a long-term illness compared with only 4 per cent of those aged between 16 and 24. The percentages are the same for men and women, but because there are more women than men in the population, the overall number of women with a disability or limiting long-term illness or both is greater than for men.

Estimates from the Family Resources Survey (Office for National Statistics, 2004a) suggested that Scotland has about one million (0.9m) disabled adults likely to be covered by the Disability Discrimination Act 1995. This amounts to almost one in five of the population (Office for National Statistics, 2004a).

Table 1.2: People with long-term illness, health problem or disability by urban/rural classification (percentages, 2001 data, all people in households)

	Base population	All people in households with disability/ long-term Illness	All people in households with disability/ long-term Illness
	(000s)	(000s)	(%)
Large urban areas	1,936	408	21
Other urban areas	1,465	289	20
Accessible small towns	522	98	19
Remote small towns	131	26	20
Accessible rural	644	108	17
Remote rural	277	50	18
Urban	4,055	821	20
Rural	921	158	17
Scotland	4,976	978	20

Source: 2001 Census (General Register Office for Scotland, 2003a)

The 2001 Census indicated that from a baseline of 5,062,000 people in Scotland, 20 per cent had a LLTI (1,028,000), and the average age of a person with a LLTI was 58 (General Register Office for Scotland, 2003a).

Across Scotland the 2001 Census found there were 978,000 people living in households with a long-term illness, health problem or disability. When this was broken down into urban and rural areas (see Table 1.2), the Census found that of those people living in rural areas, 17 per cent (158,000) have a long-term illness, health problem or disability. In remote rural areas the numbers are similar at about 18 per cent (50,000). In urban areas this rises to 20 per cent

(289,000), and in large urban areas the proportion is about 21 per cent (408,000). About 20 per cent of the population who live in small towns are disabled, but because of the small size of this population it only accounts for 26,000 disabled people altogether.

Irrespective of the exact number of disabled people, the spatial distribution, age and needs of disabled people in Scotland will have a significant impact on the planning and delivery of public services such as healthcare, learning and social care in each local area.

1.3 Attitudes towards disabled people

In trying to understand how opinions are formed we note the comments of Bob Worcester, a specialist in working with public views. He suggests that, to understand the significance of what people say when we ask for their views, we need to distinguish behaviour, knowledge, opinions, attitudes and values. Opinions are '... the ripples on the surface of the public's consciousness, shallow, and easily changed'. Attitudes are '... the currents below the surface, deeper and stronger'. Values are '... the deep tides of public mood, slow to change, but powerful' (Worcester, 2001).

Beliefs and values are important because they underpin attitudes and opinions, setting parameters for behaviour as well as for how people understand the world. The democracy think-tank Demos has coined the term 'disablism' to describe negative attitudes that exist towards disabled people. It defines disablism as 'discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others' (Demos, 2004).

Public attitudes are central to the social model of disability. Indeed, within this framework, public attitudes are the **cause** of disabilities. It is encouraging that on the surface, public attitudes in Scotland towards disabled people are strongly supportive. But while Scots tend to report positive attitudes towards disabled people, they also tend to perceive unfair treatment as common in society generally. Further, it appears that polling data for opinions towards disabled people generally are a clumsy measure of true attitudes. Ambiguous feelings towards specific impairments would seem to be more important to the experience of disabled people than measured prejudices are.

The surface attitudes that Scots express about disabled people are almost uniformly positive. For example, when asked as part of the 2004 Disability Awareness Survey if it is fair to discriminate against disabled people in the use of public transport, the vast majority of respondents, 92 per cent, said ‘No’. When asked if disabled people make a positive contribution to life in Scotland, 84 per cent said ‘Yes’, and only 2 per cent answered ‘No’ (Disability Rights Commission, 2004c).

The trend continues even when trade-offs are involved. When presented with the proposition that ‘shops and banks should be forced to make themselves easier for disabled people to use, even if this leads to higher prices’, 80 per cent of Scots indicated that they agreed (Bromley and Curtice, 2003). The Scottish Social Attitudes Survey indicates that this willingness to embrace trade-offs extends to public sector spending: 80 per cent of Scots believe that the Government should spend more on benefits for carers of the disabled (National Centre for Social Research, 2003).

While it is not at first obvious, this generally supportive attitude is also evidenced in the ‘Attitudes to Discrimination in Scotland’ report (Bromley and Curtice, 2003), despite the fact that on some occasions the report combined both negative positions and non-committal statements in its conclusions.

It is critical to note here that there is evidence that reported attitudes toward disabled people appear to be strongly shaped by stereotypes. These are likely to have a strong influence on the attitudes that emerge. There is evidence that when defining what is meant by the term ‘disability’, people often imagine the term to refer to a permanent and incapacitating physical impairment (Department for Work and Pensions, 2002a). This is a far narrower concept than the one outlined by the Disability Discrimination Act 1995. By thinking of disability in terms of particular impairments, there can be a tendency to define disabled people as limited by their impairments, rather than being constrained by environments and attitudes.

Polling of public attitudes regarding disability in general is not likely to reveal the full scope of attitudes towards all of the elements covered in the Disability Discrimination Act 1995. In short, many opinions may be masked because it seems only a few impairments are immediately called to mind by the term ‘disability’. It may be more illuminating to approach the question of public attitudes from the standpoint of particular impairments rather than of disability generally, in order to construct a fuller picture of the nuances in attitudes.

This is particularly the case for conditions, such as mental illness, that do not fit within the common stereotypes surrounding disability. A survey of hate crimes against disabled people in Scotland found that while 36 per cent of wheelchair users reported being frightened or attacked at some point, this figure was over twice as high for those with mental health problems, at 82 per cent (Disability Rights Commission, 2004d). Attitudes towards disability are unlikely to be adequately captured by surveys of ‘cross-disability’ attitudes.

Even as individuals tend to self-report positive attitudes towards disabled people, their perceptions of public attitudes are more sobering (Disability Rights Commission, 2004c). Only 15 per cent of Scots reported that they had treated disabled people differently in the past due to disability, but 61 per cent think that society in Scotland treats disabled people differently. In the same 2004 survey, 43 per cent did not believe that disabled people were being treated fairly in society.

Still, this can be seen as evidence that public attitudes are improving. In the 2003 survey, 54 per cent of Scots thought that disabled people were not treated fairly (Disability Rights Commission, 2003c). This represents a substantial increase over a single year, even though it indicates that there is more to be done. However, within the context of a social model of disability, the attitudes that people express regarding disability generally are far less important than the attitudes that are not expressed and the underlying assumptions informing their answers.

1.4 Identity of disabled people

As might be expected of such an obviously qualitative or subjective concept, the review of evidence provided little quantitative material to support a discussion of identity among disabled people. Instead, the review threw up a range of personal stories from disabled people themselves, and theoretical examinations by academics of the concepts of 'disabled identity'. What follows is a synthesis of some of the most interesting points arising from the review (see Shakespeare, 1996; Barnes & Shardlow, 1996; Hunt, 1966; Campling, date not known).

How is identity constructed?

Traditionally, the identity of different disabled individuals and groups has been constructed on the basis of their impairment, in line with a pervasive 'medical model' of disability. This process is often driven for them by their interactions with a society that emphasises the absence of physical impairment as 'normal', despite the fact that impairment is a universal facet of the human condition. All of us will be impaired at some time in our lives, perhaps temporarily when we are younger, but almost certainly with increasing regularity and severity as we get older. Yet our culture continues to perpetuate a myth of unimpaired physical capacity as the standard by which we should all be judged. Perhaps inevitably, different disabled groups have come to adopt impairment-based identities too. With the exception of one or two national overarching bodies, UK disability organisations have tended to organise on impairment-based lines.

However, the social model of disability highlights a different perspective. It explores the idea that 'disability', and therefore the identity of disabled people, is constructed for and by people with impairments through interaction with society. This can happen in a number of ways. The social model suggests that individuals and groups can come to be regarded as disabled because of discrimination which comes from the poor design of services, physical spaces and so on. This serves to erect barriers to disabled people's participation in 'normal' activities, immediately identifying those who therefore cannot participate as being 'the others' in some way.

Sometimes, in a process that can be seen as a consequence of the social model, disabled people come to regard themselves, and be regarded, as an oppressed minority. This identity can sometimes be seen among self-organised disability activist groups, who may seek to identify the ways in which they are discriminated against or oppressed in order to illustrate more powerfully their case for political action to improve their situation.

Alternatively, a person might be forced into a 'disabled' identity by otherwise well-intentioned policy development or social research, which can create a 'disabled' category or label to identify the group of people being examined by the research project or 'helped' by the policy. While this may help to direct social policies more effectively, it can be an unnecessarily arbitrary process that destroys the differences between people in order to achieve a useable definition.

A related, and very powerful, ‘identifying’ process is created by professionals working with those with impairments, particularly health and care professionals. The identification of individuals as ‘disabled’ because of the therapy or service the professionals decide they need is a very powerful source of identity for those they come into contact with. Individuals who might never have thought of themselves as disabled can be forced into that categorisation if they wish to access particular professional services.

Finally, and most obviously, individuals create their own identities, and their impairments will play a greater or lesser role in this process depending on their own experience. Some of the personal stories unearthed during the research provide very powerful statements of how an individual’s identity is constructed and maintained. Notably, it appears that some disabled people, particularly those who were not born with an impairment but who were incapacitated in some way by an accident or illness, may find it hard to assimilate a ‘disabled’ concept into their identity, and never become entirely comfortable with interacting with others on that basis.

Individuals may start off identifying themselves by their impairment, but subsequently develop broader identities through their relationships with others and through experience. One interesting example of this kind of self-identification through experience was the tendency of those with mental health problems to define themselves as ‘service-users’, or even ‘survivors’, of particular services or of particular conditions. This would certainly support the argument that our individual identity is driven in large by our interactions with others. Notably, self-identification and self-organisation on the basis of that identity seems to offer one route to greater empowerment for the individuals and groups concerned.

Other identities

There are also other factors at work in the construction of identity for disabled people. There is evidence of a link between social class and the prevalence of disability. It seems obvious that differences in social class and access to opportunity can have a significant impact on the experience of disability. But which identity is most important? A similar point can be made around questions of race, gender, religion or sexuality. It is often suggested that a disabled member of a minority ethnic group faces ‘multiple’ or ‘additional’ disadvantage or discrimination. This assumes that there is something constant in the ‘disabled’ experience, which is then added to by another experience.

However, Shakespeare (1996) reports that this basic assumption as applied to gender was questioned by some feminist researchers who examined the experience of black women and concluded that there was something qualitatively different about their experience that was not adequately described by a process of multiplication or addition of layers. There does seem to be an argument that the ‘impaired’ or ‘disabled’ element in an individual or a group’s identity can come to dominate other elements, through the way that other people respond to disability somehow differently than they do to gender, race or sexual orientation.

How do disabled people define themselves?

There is not much statistical evidence available about how disabled people identify themselves. However, from a survey commissioned by the Disability Rights Commission in 2004 (ORB, 2004) of people who were covered under the Disability Discrimination Act 1995, but did not consider themselves to be disabled, we do have some interesting information.

A survey of 1,000 disabled people found that none of them felt that ‘I am disabled’ best described them, and only 1 in

10 described themselves by saying ‘I have a disability’. More than 8 in 10 felt that the phrases ‘I suffer from …’; ‘I have …’ or ‘I have a health condition’ best described them.

Taken together, these figures seem to say that most disabled people do not define themselves as ‘disabled’ but instead as a person who is experiencing a particular condition. The person, rather than the impairment, comes first.

When asked how they felt to learn that they could legally be defined as disabled, just under 1 in 4 of the people surveyed said they were ‘comfortable’ or ‘fine’ with that definition. However, 16 per cent were ‘puzzled’ or ‘confused’, 22 per cent were either ‘upset’ or ‘angry’ and 15 per cent felt ‘patronised’ or ‘insulted’. Most worryingly, 7 per cent felt ‘depressed’ by that definition.

It would appear from these results that being identified or defined by others as ‘disabled’ can be felt by some people as a negative experience. This appears to be confirmed by the 31 per cent of respondents who felt that they had been discriminated against because of their condition. Of the respondents, 10 per cent had been ‘made to feel like a problem’, and 14 per cent felt that they had been treated differently with ‘regards to an employment-related issue’.

The ORB survey suggested that disabled people’s reactions to this discrimination vary widely. There was a gender difference: 17 per cent of women said they had done something about being treated differently, compared with only 6 per cent of men. But 84 per cent of disabled people overall had not done anything about being treated differently. Half of those who had not done anything said that the main reason was that ‘it would have made no difference’, while 31 per cent ‘would have liked to but didn’t know where to go for advice’.

How do disabled children define themselves?

Evidence from one survey found that disabled children tend to adopt an individualistic model of disability with strong medical overtones, possibly because of their high level of contact with health professionals (Connors and Stalker, 2002). Disability was seen as something belonging to them, rather than the result of society's attitudes and physical barriers. When children used the term 'disability' they were referring to their impairment, usually as they described its effects, often medical, on their lives. When asked, none of the children saw having an impairment as a 'personal tragedy'. Instead, they adopted a practical and pragmatic approach to their lives.

1.5 Summary

The surface attitudes that Scots express about disabled people are almost uniformly positive. The trend continues even when trade-offs are involved. However, there is evidence that reported attitudes towards disabled people appear to be strongly shaped by stereotypes. These are likely to have a strong influence on the attitudes that emerge. It may be more illuminating to approach the question of public attitudes from the standpoint of particular types of impairment rather than of disability generally in order to construct a fuller picture of the nuances in attitudes. This is particularly the case for conditions, such as mental illness, that do not fit within the common stereotypes surrounding disability. Attitudes towards disability are unlikely to be adequately captured by surveys of 'cross-disability' attitudes.

There is no such thing as a single, immutable 'disabled' identity. It appears that even if there are elements of shared experience within particular disabled groups, this should not be taken to imply a shared identity. The individuals within a superficially coherent group will show significant differences in the identities that they have adopted. Regardless of any similarity in their impairment, no two disabled people will adopt the same identity, because much of that identity will derive from their unique experiences of the world and their relationship with it. The evidence suggests that their ‘disability’ or impairment is only one element in a disabled person’s identity, and the significance of that one element varies greatly depending on the individual concerned, the context in which they find themselves and their experience of life. Continuing attempts at generalisation would seem bound to do disabled people a great disservice, by undermining their right and ability to pursue individual expression.

2 Communities

> Disabled people, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible (United Nations, 1975)

In this section we focus on community, because the community infrastructure is particularly important for many disabled people, especially those who are unwaged.

2.1 Living in communities

There are 800,000 households in Scotland that contain at least one person with a limiting long-term illness, health problem or disability (37 per cent of all households in Scotland) (Scottish Executive, 2004c). The Scottish Household Survey classifies households on the basis of size, age and relationships between members of the household. It reveals that households that have at least one member with a disability or long-term illness are more likely to be of one or two older adults with no children, or a single pensioner. Of households with children, 16 per cent had one or more members with a disability and 18 per cent had one or more members with a long-term illness. Nearly half (48 per cent) of the households that had one or more people with a disability were made up of single pensioners or two older adults without children (Scottish Executive, 2004c).

Evidence indicates that disabled people are more likely to live in areas of deprivation. They make up nearly 3 in 10 of the population living in the most deprived areas in Scotland, compared with only 1 in 10 in areas where there is least deprivation. Table 2.1 shows the proportion of people with limiting long-term illness in each ‘data zone’.

The data zone geography covers the whole of Scotland and nests within local authority boundaries. Data zones are groups of Census output areas which have populations of between 500 and 1,000 household residents. They have compact shape and contain households with similar social characteristics. Decile 1 is the most deprived area and decile 10 the least deprived.

Table 2.1: People with limiting long-term illness in the Scottish index of multiple deprivation data zones (thousands)

	2001			1991		
Decile	**Total**	**With LLTI**	**With no LLTI**	**Total**	**With LLTI**	**With no LLTI**
1	525	159	366	623	126	497
2	507	135	372	544	98	446
3	507	126	382	522	87	435
4	505	114	391	507	77	430
5	500	104	395	497	67	430
6	493	94	400	480	58	421
7	494	84	409	455	52	404
8	501	78	423	459	47	412
9	509	69	439	446	39	407
10	522	64	458	466	37	429
Total	5,062	1,028	4,034	4,999	687	4,311

Source: General Register Office for Scotland (2004a)

2.2 Families in communities

Disability strongly impacts on family life, and families with a disabled member (either an adult or a child) will have different needs at different times in their lives.

Families with disabled children

The early years are a critical period for disabled children, many of whom live in child poverty. Child development and future life chances are critically affected by the support and services received by young

> disabled children and their families. (Prime Minister's Strategy Unit, 2005)

There are 33,000 disabled children in Scotland (Disability Rights Commission, 2002). Children from lower income households are more likely to report that they have a longstanding illness or disability and mental health issues, reflecting a two-way relationship between low income and disability.

Children living in a lone-parent family in the UK are more likely to have their health described as 'not good' and/or having a longstanding illness/disability than those in couple families (Department for Work and Pensions, 2005). There is also a connection between the family's work status and the description of the child's health. For example, more children in families where neither parent works were likely to have their health described as 'not good' and/or having a longstanding illness/disability than children in families where at least one parent worked 16 hours a week or more.

While some disabled children require less care as they grow older, recent medical advances have ensured the survival of many children with complex impairments who require long-term, continual care, most of which is provided by their parents. Barriers facing parents of disabled children include poverty: they face up to three times the costs of parents of non-disabled children. Where families have more than one disabled child they have additional disadvantages compared with those families caring for one disabled child. These include not working and therefore being reliant on benefits, as well as an increased likelihood of lone parenthood and parental ill health or impairment (Joseph Rowntree Foundation, 1998). Parents of disabled children are much less likely to be in full-time work than parents of non-disabled children. If they do work they are often in low-quality employment, receiving state benefits to supplement their income (Contact a Family, May 2004).

Families with disabled children are often poorer, and they are often forced to live in unsuitable housing. They cannot get out and about and cannot access childcare that would enable them to go to work and break out of poverty. They cannot afford or access the activities and holidays that millions of other families take for granted (Barnardos website).

In the Children (Scotland) Act 1995, disabled children and children affected by disability in the family are identified as ‘children in need’, and local authorities are obliged to provide services to meet their needs. A number of the Scottish Executive’s ‘social justice milestones’ also focus on children’s needs, such as better childcare, better health and a reduction in the number of children living in low-income households (Disability Rights Commission, 2001).

Although there were no specific data on disabled children, monitoring of the social justice milestones indicates that since 1997 there has been a fall in the percentage of dependent children living in workless households – from 19 per cent in 1997 to 16 per cent in 2003 (Scottish Executive, 2003b).

A direct sense of isolation can be felt if parents of disabled children find themselves becoming marginalised and ignored by some family or friends (Joseph Rowntree Foundation, 2001). As a family unit they appear to be perceived as of negative rather than positive worth. Their children can also be at risk of unequal access to healthcare and education, and there can be issues about access to play and leisure activities. At the same time specialist provision often separates the children from their peers and the wider community (Joseph Rowntree Foundation, 1999).

In one survey the majority of disabled children named at least one child as an important friend (Connors and Stalker, 2002). However, those attending schools outside their neighbourhood had fewer friends at home than those who went to local schools. In the same survey, when asked, most siblings talked about their disabled brother/sister in very 'ordinary' ways, and where difference was perceived, it was seldom seen as negative. Impairment was accepted as an integral part of their sibling, whom they had no desire to change. There was a strong sense of disabled children being different but equal. Nearly all siblings in the study worried about their disabled brothers and sisters, particularly about their health and wellbeing.

Disabled adults with families

Around 15 per cent of parents in the UK will experience temporary or permanent disability while their children are still minors (Newman and Wates, 2005). The supports that disabled parents need in relation to their disability have to be sensitively attuned to their parenting role, to minimise the impact of disability on the family unit. Difficulties can arise where parents cannot access the support services that they might need and have to rely on their children for support.

While the caring role of adults has been recognised for many years, the caring role played by many young people has only been acknowledged relatively recently. The 2001 Census put the figure of young carers at just under 17,000. However, the Princess Royal Trust for Carers estimates there are 115,000 young carers in Scotland (BBC News Online, 6 June 2005 and BBC News Online, 27 October 2004). Experts estimate that up to 14 per cent of 7–19-year-olds in Scotland look after someone with an illness, disability or health problem (BBC News Online, 27 October 2004).

The **Community Care and Health (Scotland) Act 2002** enhanced carers' rights and entitled under-16s who are involved in caring to be assessed as a carer and to have access to help and information to support them in their caring role. The Act placed duties on local authorities and the NHS to inform carers of their rights and available support. Although actions such as these are beginning to recognise the important caring role many young people undertake, in conducting this review we found no evidence of any longitudinal studies designed to examine the long-term effects on young people who provide care. Research by Edinburgh University found that 45 per cent of young carers surveyed were being referred to mental health services because of the burden of care on them (BBC News Online, 27 October 2004).

Integrated support across community care and children's services and timely access to information, advocacy advice and peer support can be difficult to get hold of. Disabled parents can also experience unequal access to health and other mainstream services for themselves and their children (Joseph Rowntree Foundation, 2003).

Disability benefits do not take account of the additional costs of parenting for disabled adults (ibid), and parenting tasks and roles are rarely specified in eligibility criteria for assessing community care provision (Joseph Rowntree Foundation, 2002a).

Isolation, and assumptions about how a family unit functions, appear to have a direct impact on the children of disabled parents. Disabled parents may face assumptions that their impairment leads to child deprivation, potential harm or abuse. Some social care professionals believe that disabled parents are in need of care rather than assistance and that their children would be better off with a non-disabled parent (Joseph Rowntree Foundation, 2003). There is some evidence that research focus on 'young carers' may have resulted in skewing policies and practice away from how best to support the children and their families while ignoring what works in supporting disabled parents (Morris, 2003).

2.3 Social participation in communities

Community, as defined geographically, is particularly important in terms of administrative boundaries and service delivery, but people have many common interests other than place. Alternative communities can be characterised around interests, where members of a group have something in common with each other and this commonality in some way distinguishes them from members of other possible groups.

Social networks

Social networks in the broader geographical community also shape quality of life; therefore it is important to understand the dynamics that support social participation. Social participation has several meanings, of which three provide a useful focus here (Burton et. al, 2004):

- involvement by individuals or community/voluntary sector representatives in public policy
- direct participation in community-based or voluntary organisations
- informal connections through families, friends and neighbours.

Social participation has been highlighted as important to personal health and wellbeing (Elrick, 2003). Barriers to social participation can be as basic as living away from families and friends, or lacking the confidence or scope to broaden personal social networks. Disabled adults are less likely to visit or go out with their relatives and friends, compared with those without a disability or long-term illness, but they are more likely to have had relatives round to visit in the last two weeks (Scottish Executive, 2004c).

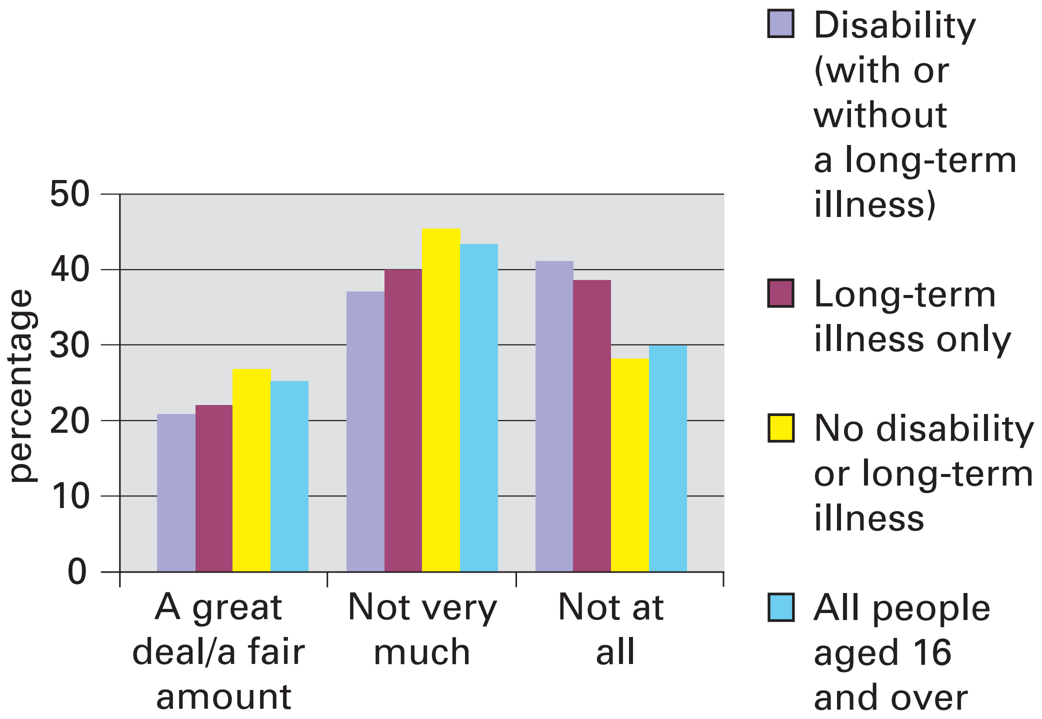
Community involvement

Wider community involvement can set out to include all the population of an area. Some studies, however, focus on the effectiveness of initiatives in involving particular types of individuals, groups and representatives. Edwards (2002) suggests that ways of improving the involvement of disabled people include:

- understanding disability in terms of the social rather than the medical model
- ensuring that programme managers are aware of the Disability Discrimination Act 1995 and their responsibilities under the Act
- enhancing involvement at strategic level and making sure that information is accessible.

Awareness of disabled people's statutory rights, as well as relevant needs and issues, is therefore a priority not only for disabled people themselves, but also for those responsible for planning and delivering services.

Figure 2.1: How involved adults feel in their local community 2001–02

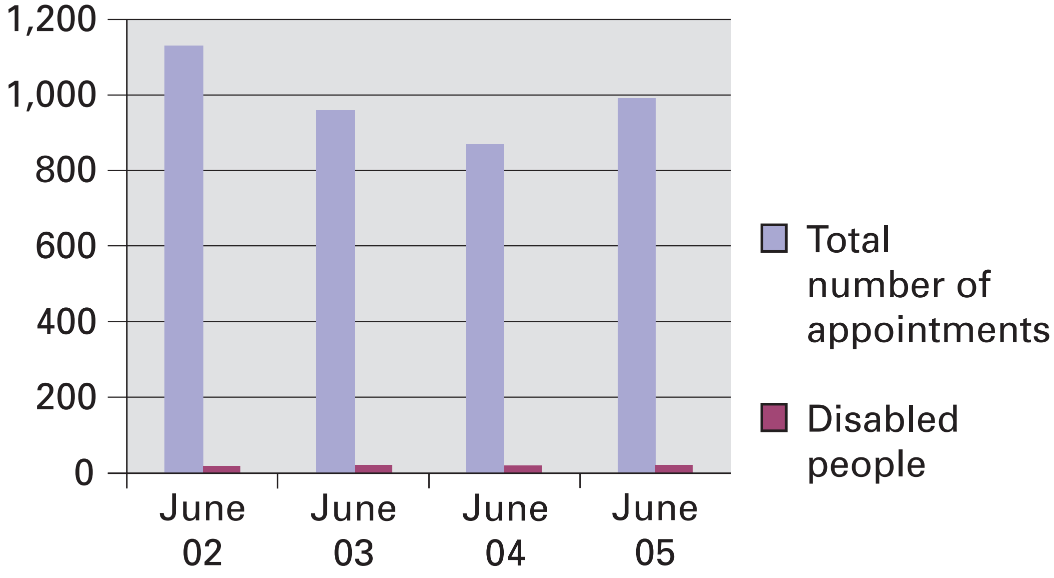


Source: Scottish Executive (2003d)

People with an impairment or long-term illness feel less involved in their local community than those who have no impairment or long-term illness (Scottish Executive, 2004c). According to the Scottish Housing Survey, 26 per cent of adults in Scotland said they felt fairly involved in their community, compared with 22 per cent with a long-term illness, and 21 per cent with a disability only. 30 per cent of adults in Scotland said they did not feel involved in their community, compared with 41 per cent of those who are disabled and 38 per cent of those dealing with long-term illness (Figure 2.1).

Disabled people hold fewer public appointments than others in the community or wider society. Between June 2002 and June 2005 the proportion of people in public appointments who were disabled rose from 1.8 per cent to 2.5 per cent, which represents one additional disabled person (Figure 2.2).

Figure 2.2: Public appointments June 2002 to June 2005



Source: Scottish Executive (2005d)

Voting

One of the basic rights of citizenship is the right to vote. Research by Capability Scotland (2005) has shown that there were major access problems at 43 per cent of polling stations in 1999, 40 per cent in 2001, and 17 per cent in 2003. The main issues were inaccessible buildings and the lack of a secret ballot. Going against the trend of reduced participation in the formal electoral system, research continues to suggest that disabled people and their carers are highly motivated to turn out and vote.

Changes introduced under the Representation of the People Act 2000 included a large-print version of the ballot paper on display. People with a physical disability could also take a companion with them to help them vote if needed. Technology can help overcome some physical access problems. The virtual polling station, developed in Scotland by Capability Scotland and sponsored by the Electoral Commission, was the first project of its kind in the UK, using Internet technology to take disabled voters through a 'virtual' voting process.

Volunteering

Volunteering and disability are important for two reasons:

- the support provided to disabled people through voluntary organisations
- opportunities for disabled people to give their time and abilities in support of others.

Volunteering is seen as a right for individuals and a benefit for communities and society as a whole. There is a growing body of evidence that volunteering helps people to develop self-confidence, self-esteem and social networks, as well as providing opportunities for skills development (Elrick et. al, 2002). Some projects have been developed to create interactive support for people in need. For instance, a project focused on supporting older people offered the opportunity for those who were feeling well enough to take on a volunteering role: during times of need they were themselves able to access the services provided (Elrick and Gamble, 2004).

In 2001 and 2002, disabled adults and those with a long-term illness were significantly less likely to give up their time as a volunteer. Only 17 per cent and 18 per cent of them respectively helped clubs, charities, campaigns or organisations in an unpaid capacity over the previous 12 months. This compares to 28 per cent of adults without a disability who volunteered (Scottish Executive, 2003d).

Research exploring the attitudes of organisations that use volunteers found that many disabled people said that they had never been asked to volunteer. Some of the barriers identified related to the benefits system, the need for supportive intermediaries to ease the path into volunteering, and physical access (Murphy, 2001). Access to volunteering is an important element of equality, and may require additional support for some people (Elrick et. al, 2002). The benefits in terms of social participation, a sense of self-worth from helping people, learning new skills and making new friends can have a direct impact on people's health and wellbeing (Elrick, 2003).

Volunteering has an important role in increasing people's awareness of issues facing others, their understanding of decision-making processes, and their ability to participate as active citizens at local and national levels.

2.4 Policies to support communities

In policy terms communities are the focus for delivering a range of services and for identifying priority investment.

Disabled people are more likely than other people to be out of work and in receipt of benefits and health and social services support. They are key target groups for action in relation to inclusion and likely to be suffering from multiple deprivation.

Measuring deprivation is an essential element of the Scottish Executive's approach to social justice and social inclusion. The Scottish Centre for Research and Social Justice made a key recommendation that the Executive should develop measures of deprivation at the individual level. This would be based on Townsend's definition of multiple deprivation, which includes physical needs and social dimensions, such as visiting family and having friends (Bailey et. al, 2000). It would offer opportunities to focus on the needs of individuals and different groups of disabled people within a broader context. It would also increase understanding of the nature of community and social support that might impact on the quality of life of disabled people.

In 'Closing the Opportunity Gap', the Scottish Executive identified the need to focus core public services in disadvantaged areas to make them more effective (Scottish Executive, 2002a). Five priority areas were identified: health, education, transport, crime and jobs. A second focus was on supporting 'social capital', defined as the skills, confidence, support networks and resources that people need.

The community planning process is intended to promote equal opportunities, but there are no specific provisions covering planning for disabled people. Accessibility and links to public transport are briefly mentioned in the original 'Planning Policy Guidelines' as general social justice priorities, but there is no general prioritisation of health, housing, education and learning or social care (Scottish Executive, 2002e).

Community planning could offer a valuable opportunity for engaging disabled people and setting agendas. The community planning process can help disabled people in communities access services tailored to their needs, as well as offering a way to influence how priorities are established (Scottish Executive, 2002a). The quality of life of individuals, of any age, is intimately linked to their ability to access what they need when they need it, their sense of self-worth and the quality of their social connections. These needs are highly significant for someone who has a disability.

For the longer term there are practical challenges in building communities that have the best possible social and physical infrastructure, in ways that support diversity. The introduction of the disability equality duty from December 2006 will place a requirement on all public authorities to eliminate discrimination and actively promote equality, and has the potential to pave the way for more inclusive design and delivery of services in local areas.

2.5 Summary

Disabled people are more likely than others to live in areas of deprivation. They make up nearly 1 in 3 of the population living in the most deprived areas in Scotland, compared with only 1 in 10 in areas where there is least deprivation.

Disability strongly impacts on family life. Families with a disabled member will have a number of different needs at different stages of their lives. The future life-chances of children who are disabled or have disabled parents are critically affected by the support and services received by their families.

Disabled people hold fewer public appointments than others in the community. People with a disability feel less involved in their local community than those without a disability, and are also less likely to volunteer.

The quality of life of individuals, of any age, is intimately linked to their ability to access what they need when they need it, their sense of self-worth and the quality of their social connections. In policy terms, communities are the focus for delivering a range of services and for identifying priority investment. So the community planning process could be an important route for disabled people to influence how local priorities are established. For the longer term there are practical challenges in building communities that are inclusive and provide the best possible social and physical infrastructure in ways that support the needs of all residents.

3 Housing

> The new Housing (Scotland) Act 2001 will ensure the housing needs of disabled people become key priorities for Scotland's local authorities. The Executive is committed to improving the physical living conditions of disabled people. And we are driving forward several measures to make that vision a reality. We are examining ways of providing more adaptations in properties and set a target of 20,000 new and improved homes over the next three years for affordable or low cost owner occupation.
> (Scottish Executive, 2001)

In this section we explore disabled people's experiences of accessing housing that is suitable and appropriate to meet their needs.

3.1 Disabled people: their households and where they live

The 2001 Census showed that there were just under 2.2 million households in Scotland, of which 17 per cent contained at least one person with a disability, and 13 per cent contained at least one person with a long-term illness. It is estimated that currently between 30 per cent and 37 per cent of households in Scotland have someone with a 'limiting long-term illness or disability' (Scottish Executive, 2004c).

Older people make up almost half of disabled households. Data from the Scottish Household Survey for 2001 and 2002 illustrate that 48 per cent of disabled households are classified as either older smaller households[1] (24 per cent), or single pensioner (24 per cent) households. Single adult

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[1] Older smaller households contain one adult of non-pensionable age and one of pensionable age and no children, or two adults of pensionable age and no children

households account for 13 per cent of disabled households, while 7 per cent are small family homes (Scottish Executive, 2004c). By contrast, older smaller and single pensioner households together make up only 21 per cent of households in which no residents have a disability or long-term illness.

Table 3.1: Percentage of rented housing in Scotland

Households	Local authority	Housing association	Private landlord	Other
Households with one person with a disability with or without a long-term illness	73	19	6	1
Households with one person or more with a long-term illness only	75	16	7	2
Households with no persons with long-term illness or disability	60	16	20	4
All households	66	17	14	3

Source: Scottish Household Survey, Tenure 2001–02

Disabled households are significantly more likely to rent their homes, compared with non-disabled households. As Table 3.1 shows, the majority of those who rent their accommodation rent from their local authority. A rented local authority property is home for 73 per cent of households with one person with a disability with or without a long-term illness, and for 75 per cent of households with one or more persons with a long-term illness only). Around 6 per cent rent from a private landlord, as opposed to 20 per cent of households with no long-term illness or disability (Scottish Executive, 2004c). Disabled people and their families are twice as likely to live in the social rented sector as non-disabled households, possibly reflecting the fact that disabled people and their families tend to have lower than average incomes, as well as above average living costs (Communities Scotland, 2004).

Disabled people are less likely to move: 33 per cent of disabled adults have remained in their current homes for more than 20 years, while only 20 per cent of adults without a disability or long-term illness have done so. This may be because of the age demographic of disabled people or a long-term illness: 47 per cent of all people aged 60–74, and 51 per cent of those aged 75 plus, have been in their current home for more than 20 years (Scottish Executive, 2003d).

Around 64 per cent of Scottish households live in a house or bungalow and 36 per cent live in a flat or maisonette. For disabled households these figures are 60 per cent and 39 per cent respectively, showing no significant difference.

Only 38 per cent of disabled Scots own their property (Disability Rights Commission, 2001). This is a small proportion compared with the equivalent figure for the Scottish population as a whole (of whom 57 per cent are home owners) and disabled people elsewhere in Britain (of whom 46 per cent are home owners). It is therefore not surprising to find that households with one or more disabled persons are also half as likely as households with non-disabled people to have a mortgage.

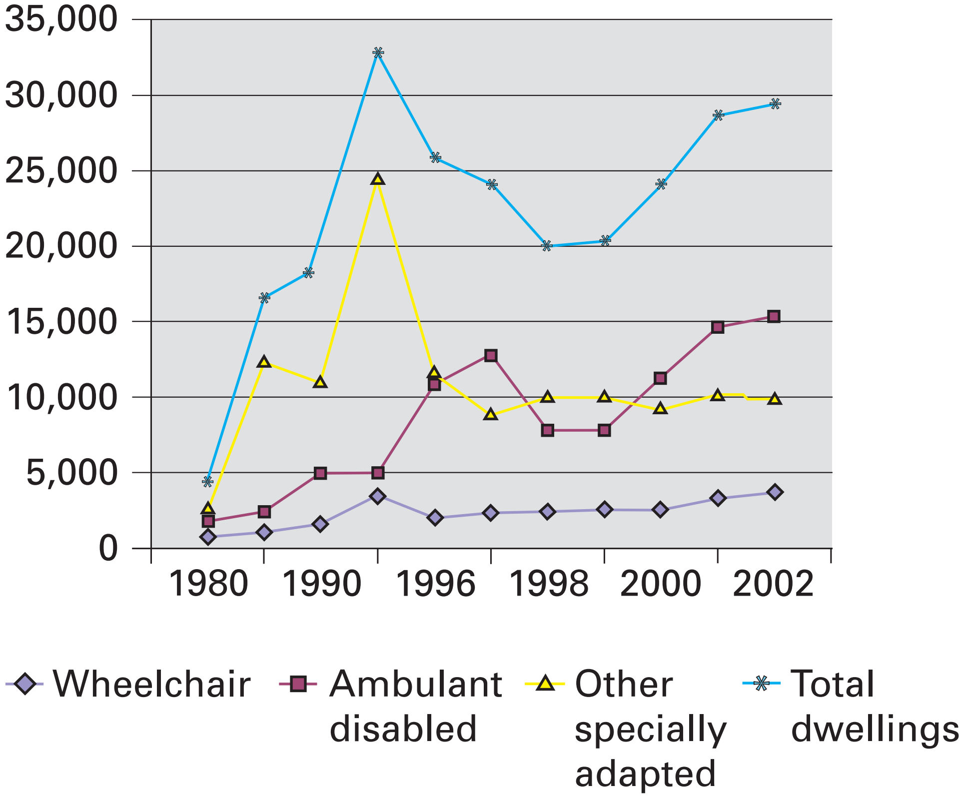
3.2 Disabled people's access to housing that meets their needs

Nearly 20 per cent of adults with a disability or long-term illness could benefit from an adaptation or piece of special equipment. This figure rises to 28 per cent for those who have both a disability and a long-term illness.

Approximately 12 per cent of homes have an adaptation to meet the needs of a disabled person, accounting for 254,000 homes (Disability Rights Commission, 2001).

Communities Scotland, in partnership with local authorities and housing associations, fund a significant proportion of the special needs housing in Scotland. In 2002, public agencies provided 29,227 homes adapted to meet special needs, an increase from 20,121 homes in 1998 (Scottish Executive, 2004c).

Figure 3.1: Numbers of special needs housing for disabled people provided by public agencies and housing associations, 1980–2002



Source: Scottish Executive (2004c)

Figure 3.1 shows the trends in the volume of special needs housing for disabled people. The figure rose from 4,000 in 1980 to 29,000 in 2002, falling from a high of 33,000 in 1995. In 1980, 500 of these were designed for wheelchair access: by 2002 the figure had risen to 3,800. The biggest increase was in houses for ambulant disabled people[2], rising from 1,300 in 1980 to 15,500 in 2002.

In general, the older adults are, the more likely they are to need special equipment or adaptations to their home: 12 per cent of people aged 16–24 with a disability or long-term illness need an adaptation or equipment, with the figure rising to 23 per cent for those aged over 75.

A baseline report produced by Audit Scotland (2004) demonstrated some of the complexities involved in providing adaptations. Responsibility for providing these is split between local authorities (social work and housing) and the health service (both acute and primary care). Local authorities provide equipment that meets social need, and the health service is responsible for equipment that meets nursing need in the home setting. The Audit Scotland (2004) report found:

- services are fragmented and the split in responsibilities is unhelpful and confusing for users and providers
- information on the services is not easy to access and some people have to wait for a long time for adaptations and equipment
- there is a lack of formal policies and procedures in many places, exposing users and providers to risk
- equipment and adaptations that people get, and whether they have to pay, depend on where they live.

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[2] 'Ambulant disabled' defines people who walk with difficulty and insecurity, using canes, braces, crutches or other aids

Barriers in the way of disabled people's access to housing include shortages of the right type, size, location or 'adaptability' of houses. Low income, coupled with the cost of suitable properties, can also result in funding gaps. Underlying issues such as attitudinal barriers can have an impact on accessing housing options (Communities Scotland, 2004).

One study in Lothian by the Disabled Person's Housing Service found that properties that have been adapted are often under-used in meeting the accommodation needs of disabled individuals. The study found that only 40 per cent of properties adapted for wheelchair users in the area were actually occupied by a person using a wheelchair.

Advice online from Shelter for disabled people about buying a new home suggests that new-build homes should now be designed to be 'barrier free' (Shelter website, undated). This means they are more accessible and can be adapted more easily and economically to suit the needs of disabled people.

For example, new-build homes must in Shelter's opinion:

- be easily accessible from the road or parking area
- have adequate space, wide enough corridors and suitable doors for wheelchair users to move around easily
- allow access to essential rooms such as the bathroom and kitchen
- have a toilet or bathroom on the ground floor
- allow easy access to all fittings and controls, such as light switches, plug sockets and controls for the heating
- leave room for a stair lift to be installed, if the home has stairs.

Housing choices, already limited by income for many, are more complex for disabled people than for the population as a whole. Being near services is a priority for some, particularly services that provide essential support relating to a person's disability. Access to more general services, such as shopping facilities, schools and public service providers, can also be important. There would appear to be a lack of suitable and affordable housing in the owner-occupation market and the private rented sector. It is important that consideration of the housing needs of disabled people is integral to building development plans within both the private and social housing sectors. This includes building houses that can be adapted in ways that will support disabled people. Choosing to move from the social rented to the private sector appears to be more difficult for disabled people. Consideration of disabled people's interests is important if establishing rent-to-buy developments, or in working with private developers to build a mix of housing.

Ownership Options specialise in home ownership for disabled people in Scotland. It suggests that the owner-occupier sector in Scotland offers untapped potential for meeting the needs of disabled people. However, raising mortgage finance is a major hurdle that needs to be overcome before home ownership can be a mainstream process for disabled people.

The Housing (Scotland) Bill going through the Scottish Parliament at the time of writing (2005) might help disabled people in accessing suitable and appropriate housing. Early indications suggest the Parliament's Communities Committee has called for improved grants and rights for disabled people, following Stage 1 scrutiny of the Bill. The Committee has indicated there must be improved provision for disabled people, particularly in relation to mandatory grants for adaptations. The Committee has also called for a provision that landlords should not unreasonably withhold consent for disabled tenants to make adaptations.

Table 3.2 shows that the largest group of people in receipt of housing support is older people, at 55 per cent (76,900). People with a range of impairments or illnesses make up at least 16 per cent of the total. This 16 per cent is made up of people with a physical disability/illness (5,600), people with mental health problems (5,200) and people with learning difficulties (5,700).

Table 3.2: Number of clients receiving housing support during 2003–04 by client group: Scotland level

Clients receiving housing support during 2003–04	Number
Older people	76,900
People who are homeless or sleeping rough	19,100
Physical disability/illness	5,600
People having mental health problems	5,200
People with a learning disability	5,700
People who use alcohol	2,200
Vulnerable due to young age	2,500
Women at risk of domestic violence	2,000
People who use drugs	1,200
People with poor social skills or disruptive behaviour	1,300
Other client groups	1,700
Other vulnerable groups	20,800

Source: Scottish Executive (2004e)

A UK survey of 3,000 parents undertaken by the University of York found that 9 out of 10 families with a disabled child reported at least one difficulty with their housing (Joseph Rowntree Foundation, 2003). Over a third reported problems with the location of their home, either because the environment was not safe for their child or because they had encountered difficulties with neighbours. Many reported that they had not received sufficient help from statutory agencies, highlighting the point that no one public agency has overall responsibility for meeting the housing needs of disabled people. Only 1 in 10 families in the study reported that they had received financial assistance in adapting their home to meet the needs of disabled children. Most indicated that they would prefer to move rather than adapt their current property, a trend which requires further enquiry in order to determine what measures can be offered to affected families to spare them the perceived necessity of uprooting for alternative accommodation.

3.3 Summary

Disabled people and their families are twice as likely to live in the social rented sector as other households overall. This possibly reflects the fact that disabled people and their families tend to have lower than average incomes, as well as above average living costs.

Housing choices, already limited by income for many, are more complex for disabled people than for the population as a whole. Being near some services is a priority for some, not only services that provide essential support relating to a person’s disability, but also more general services, such as shopping facilities, schools and public service providers.

Barriers in the way of disabled people’s access to housing include shortages of houses of the right type, size, location and suitability for adaptation; and the complexities of the adaptations process. Low income, coupled with the cost of suitable properties, can also result in funding gaps. Underlying issues such as attitudinal barriers can have an impact on accessing housing options.

4 Transport

> Transport is one of our most vital public services, influencing our economy, our communities, our environment, our health and our quality of life. It touches all our lives: it connects people to jobs, family and friends, students to learning, customers to services, businesses to suppliers, products to markets, and Scotland to the world. A transport system that serves people and businesses well is fundamental to achieving our vision of a prosperous and socially-just Scotland. (Scottish Executive, 2004d)

In this chapter we explore what still needs to be addressed now that transport policy is within the remit of the Scottish Parliament. However, disabled people's rights regarding transport matters are reserved to Westminster, hence the forthcoming changes in the Disability Discrimination Act 2005. There will be a new Code of Practice aimed at helping disabled people and transport providers understand and implement new duties under the Disability Discrimination Act 2005. The Code of Practice comes in advance of changes in the law due to take effect in 2006, when Britain's transport operators will need to ensure that disabled people are treated fairly on the country's transport system.

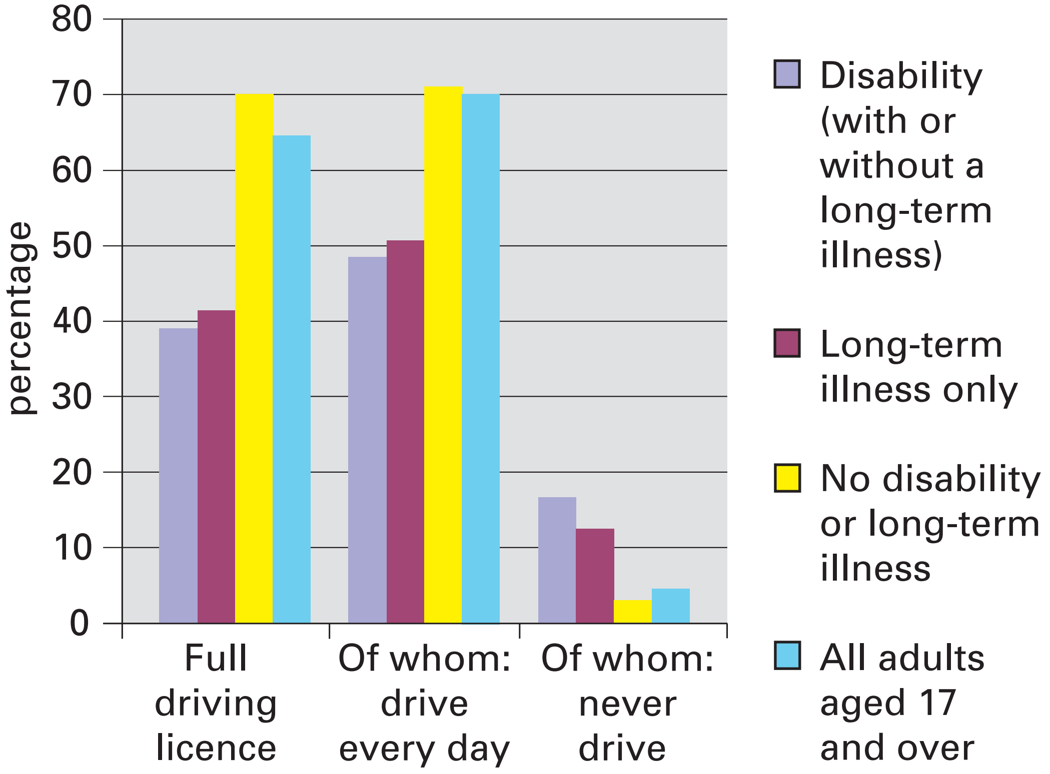
4.1 Use of various modes of transport

In this section the evidence is separated into various forms of transport, but in many instances disabled people use more than one form of transport to undertake their journey. It is therefore important that whole journeys are barrier free, irrespective of which forms of transport are used.

Use and availability of cars

The Scottish Household Survey 2001–02 estimates that more than half of people aged 17 or over hold a full driving licence, but found there were significant differences between the disabled and non-disabled population (see Figure 4.1) (Scottish Executive, 2004c). Almost three-quarters of non-disabled people aged 17 or over hold a full driving licence, compared with two-fifths of disabled people. The same survey found that over two-thirds of all people aged 17 or older who hold a full driver's licence drive every day, but non-disabled people are significantly more likely to drive every day. Differences also exist between men and women: over three-quarters of men hold a licence compared with only just over half of women. The difference between disabled men and women is even greater. The same survey found that twice as many disabled men hold licences compared with disabled women. Households with a disabled member are less likely to have access to cars.

Figure 4.1: Proportion of adults aged 17 and over holding a full driving licence, and frequency of driving, 2001–02



Source: Scottish Executive (2003d)

The Blue Badge is given to some disabled people who find it difficult to get around without using a car. The number of Blue Badge holders has increased from 210,000 holders in 2002 to 224,000 holders in 2004 (Disability Rights Commission, 2004a).

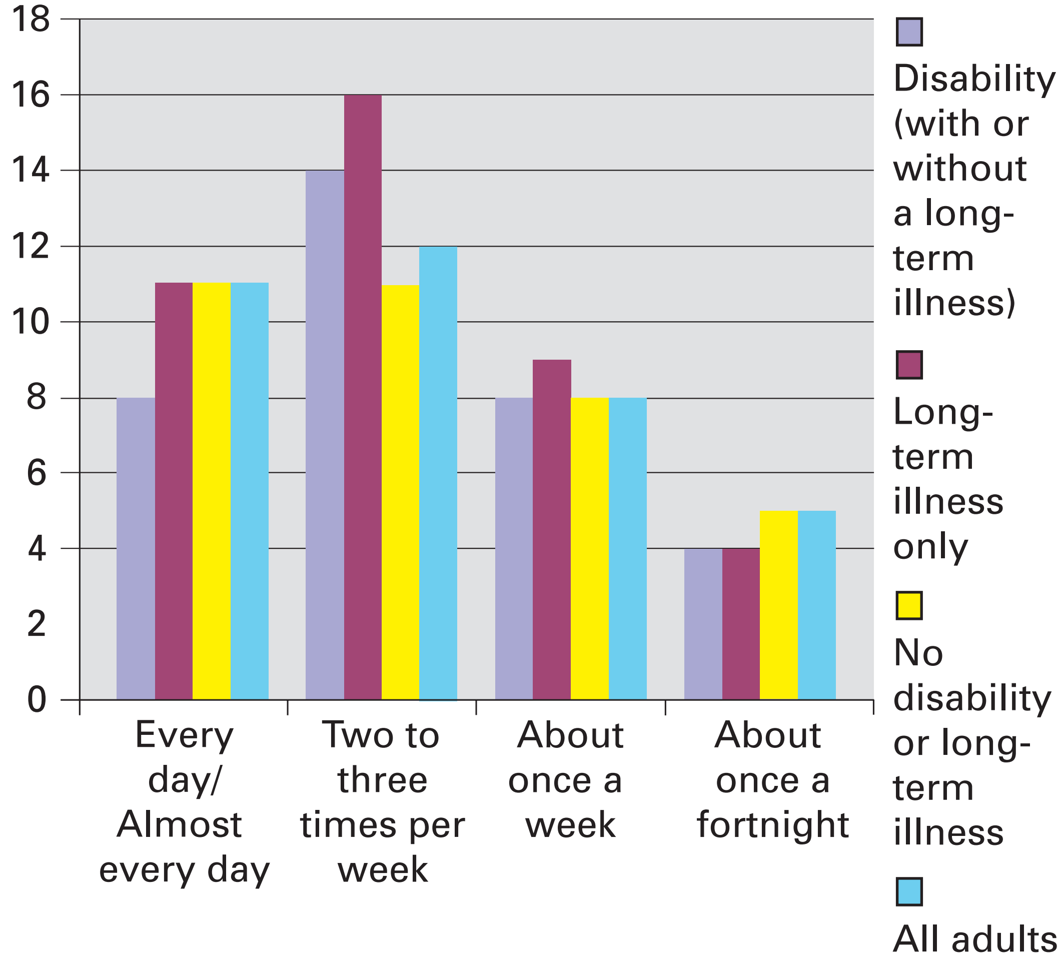
Use and availability of buses

Disabled people in Scotland are able to travel free on public transport, using an off-peak pass funded by the Scottish Executive (from October 2002), which entitles holders to free concessionary bus travel within their local authority boundary (Wilson, 2003). However, cost may not be the only issue determining disabled people's use of buses.

Data from a 1998 study of transport provision for disabled people by Reid-Howie found that buses generally did not have low floors (12 per cent of buses in operation in Scotland had low floors) (Reid-Howie, 1999). Around half of providers when asked said they had no plans to introduce low-floor buses within a three-year timeframe. Access to low-floor buses makes travelling by bus easier not just for those with physical disabilities, but also for pregnant women, older citizens and parents of young children with prams and pushchairs. Mainstreaming good design benefits all sections of society.

In a later review by Reid-Howie (2004), findings indicated that the accessibility of low-floor buses was still a matter of concern to many disabled people. A large number of wheelchair users cannot use current low-floor buses, and it is clear that the layout represents a disincentive to a significant number of older and disabled people. The issue of lowering buses was found to be a point of contention between disabled people and bus drivers. The current conduct regulations offer a measure of discretion to drivers. The researchers found evidence that many disabled people, and many older people, will not ask for the bus to be lowered, but did not explain what prompted their decision.

Figure 4.2: Frequency of using bus service in past month, 2002



Source: Scottish Household Survey 2002

The 2002 Scottish Household Survey asked adults how often they used their local bus service in the past month, if at all. Perceptions of the disabled and non-disabled populations are broadly similar and on the whole fairly positive (Scottish Executive, 2004c). There was one small, but notable, difference. Just over 6 out of 10 disabled adults agreed with the statement ‘It’s easy changing from buses to other forms of transport’; this compared with just over 7 out of 10 non-disabled people. Just under half of all adults with a disability did not use their local bus service more often because of health reasons. Almost one-fifth of disabled adults suggested they are more likely not to use buses because of the difficulties involved in access (on/off steps).

Use and availability of trains

The Reid-Howie (2004) report referred to a national agreement binding all train operating companies and Network Rail to providing a seamless and transparent service to disabled people. However, findings showed that access to platforms on railway stations (including unstaffed stations) was difficult on occasions: 35 per cent of railway stations in Scotland were estimated to be inaccessible or only partly accessible. This impacts not only on those with physical disabilities, but also on travellers with large suitcases and parents of young children with prams and pushchairs.

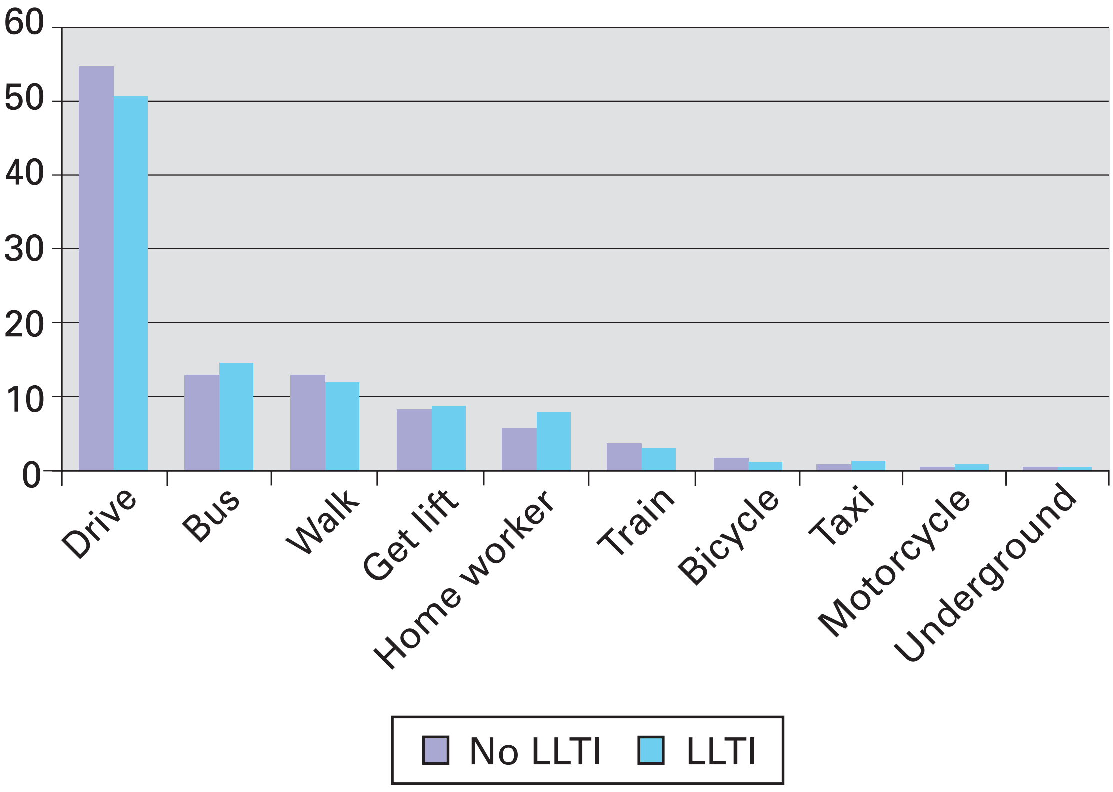
There is a national booking service for disabled people (which has a range of accessibility enhancements). Any needs notified to this service are distributed to all of the operators likely to have contact with the disabled person over their journey (including any train operating companies and station staff). In the view of contributors to the research, this approach tends to work patchily (Reid-Howie, 2004). Most disabled people had experience of some aspect of assistance not being delivered either on time or at all, but against this, it was clear that many journeys proceeded with no difficulties at all.

The lack of accessible stations has an impact on the extent to which people with mobility impairments can travel independently. There are also a large number of stations where only one platform is accessible, making return journeys very difficult for many disabled people. One key frustration found by the Reid-Howie reports is that in rural stations trains can be diverted without warning to inaccessible platforms.

Evidence from the Scottish Household Survey (2002) found that when asked about rail travel, most disabled adults (over 9 out of 10) had never used a train service during the past month. Disabled adults surveyed were more likely to use buses than trains.[3]

4.2 Use of public transport while travelling to work

Figure 4.3: Method of travel to work by limiting long-term illness (LLTI) (percentage of people in employment)



Source: 2001 Census

Figure 4.3 shows that there is little difference in the modes of transport used by disabled and non-disabled people when travelling to work (Riddell et. al, 2005). More than 50

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[3] The Scottish Household Survey does not collect any information on why people have not used a train service more often.

per cent of all people, irrespective of disability status, drove to work; between 10 and 15 per cent took a bus or walked; and just under 10 per cent got a lift. A slightly higher proportion of people with limiting long-term illness worked at home. There was little difference in the distance travelled to work between people with and without limiting long-term illness.

4.3 Experiences of using public transport

A survey of 373 disabled people and carers of disabled people by Capability Scotland (2004) found that bus or coach, and car or van, were the most popular forms of transport. The same survey also found that taxis were popular, being used as a regular form of transport by 1 in 5 respondents. However, 2 out of 3 people felt that the cost of taxis meant they could not go out as often as they would like.

Further research by Capability Scotland (Ryan, 2004) found that inappropriate public transport provision contributes to the social exclusion and disadvantage of disabled people in every area of life. The research found that disabled people spend more on transport but go out less than other sections of the population. In the view of the researcher, inadequate public transport provision could:

- limit the educational choices of adults and children
- cause people to miss healthcare appointments, causing knock-on effects as many have to wait months for another appointment
- affect people's ability to socialise, limit choices of where to shop and prevent people from going on holiday or on day trips together
- prevent people from looking for work, attending interviews and accepting offers of work, and limit where people can work and what hours they can work.

Lack of available and suitable transport remains an issue for disabled people, as evidenced by survey and research evidence (Reid-Howie, 2004). For example, 1 in 4 disabled people experience difficulty getting on and off buses and trains (Social Exclusion Unit, 2004). Other difficulties include transfers between modes of transport requiring a substantial wait, and associated costs for those on low incomes (Reid-Howie, 2004).

Many visually impaired people were found to have little confidence that, for example, audible announcements will be made on trains, or that bus drivers will remember to let them know when their stop is approaching. Rail passengers in rural areas were found to have little confidence that their train will return to an accessible platform.

With taxis, findings indicated that although there had been some increase in the number of accessible vehicles, this remained patchy, and there were large areas of Scotland where only saloon cars operated. Many disabled people will not travel by taxi, as they are unable to be guaranteed that an accessible vehicle will be available for the return journey (Reid-Howie, 2004). However, from December 2006 taxis will be subject to the Disability Discrimination Act 2005 duties and will no longer be able to discriminate against disabled people.

The introduction of Regional Transport Partnerships may in the longer term help resolve some of the issues facing disabled people, by taking a strategic and ‘joined-up’ approach to journeys and transport needs. However, ‘connectivity’ will in many instances go beyond existing boundaries and these will also require to be considered (Scottish Executive, 2004h).

A review of services that looked specifically at people with learning disabilities found that getting around meant a lot to them (Scottish Executive, 2003a). Those taking part in the service review were not satisfied with local transport services, although developments such as the Scottish Executive's rural transport initiative were helping certain areas. The report suggested that timetables needed to be very clear if people are to understand them.

4.4 Summary

At the beginning of this section transport was identified as one of our most vital public services. Recognition of 'whole journeys' is important because many disabled people rely on more than one form of transport when travelling: for example, people may need to take the bus to the railway station. Physical access, although important, is only part of the problem. Many visually impaired people have experienced difficulties because of small-print timetables or a lack of audible announcements. Evidence suggests that lack of availability, poor accessibility, and cost in relation to transport mean disabled people in particular are less able than many other sections of the population to connect with social, educational and purchasing opportunities, which contributes to social exclusion and disadvantage. Improvements may come as a result of the introduction of the Disability Discrimination Act 2005. However, as with any other changes, these may take some time to become embedded.

5 Access to goods and services

In this section we explore the experiences of disabled people in accessing basic goods and services, in order to identify any differences between disabled and non-disabled groups.

Part 3 of the Disability Discrimination Act 1995 makes it unlawful for those who provide goods, facilities and services to discriminate against disabled people. Since October 2004, service providers have had a duty to make reasonable adjustments to the physical features of their premises that make it impossible or unreasonably difficult for a disabled person to use their services. However, as we saw in the previous chapter, access to premises might not be the only issue. Disabled people without cars may find it more difficult to reach services in the first place, especially in rural areas where public transport networks are less dense.

The most recent estimate of the annual spending power of disabled people in Britain (those covered by the Disability Discrimination Act 1995) is around £80 billion (Department for Work and Pensions, 2004). In Scotland, disabled people spend around £5 billion a year on goods and services, about 16 per cent of total consumer spending (Capability Scotland, 2004).

5.1 Experience of accessing goods and services

In the Disability Awareness Survey 2003, almost 8 in 10 of the respondents felt that the most important disability access issue was to ensure cafés, shops and banks were more accessible to disabled people (Disability Rights Commission, 2003c). The majority of respondents perceived that not enough was being done to make sure that disabled people could use services in the same way as non-disabled people.

Another survey (Chowdhury and Worley, 2003) suggested that the factor that caused the most difficulty for just over half of disabled customers was heavy doors, followed closely by steps at the entrance to a building. Around 2 out of 5 respondents considered positive attitudes of staff towards disabled people as having the most influence on them continuing to use a service.

In the same survey almost 4 out of 10 Scottish respondents with mobility and sensory impairments said they have difficulty accessing goods and services. For example, difficulties in access during an appointment or visit to a hospital or clinic were cited by about a quarter of respondents, and just under a fifth cited difficulties in accessing a dentist. When respondents were asked if, when sourcing goods and services, they 'felt like they were treated as a normal person', 35 per cent of Scots said they did. Quality of service was also important for Scottish respondents.

A mystery shopper survey by Capability Scotland in leisure outlets found that a key requirement for disabled people in places like cinemas, theatres and pubs was availability of disabled seating (Capability Scotland, 2003a). However, only just over half of outlets visited had this facility. Low counters/ticket booths were uncommon (24 per cent), as were induction loops at counters and ticket booths (11 per cent) and outlets were fairly unlikely to have alternative formats for menus, programmes or other information that customers would use. In three-quarters of outlets that did not have alternative formats there was no offer of an alternative, nor did staff offer to help. For those outlets where staff did offer to help, this included reading menus and making suggestions about food choices.

Based on the mystery shoppers' experiences, the store types with the highest rating of shopping experience were:

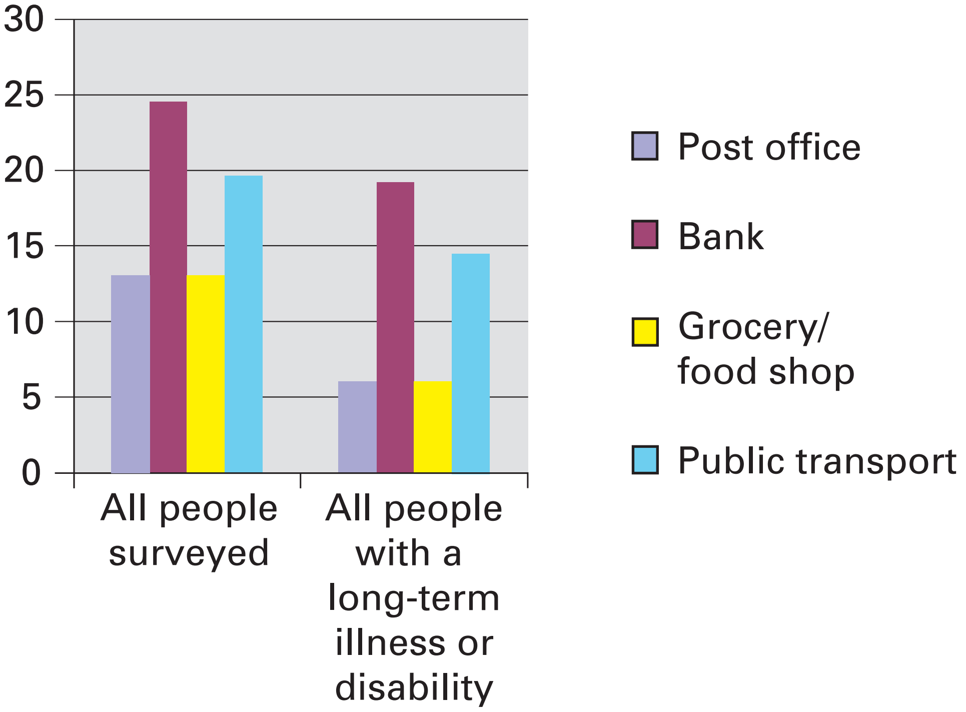
- national supermarket chains
- national clothes shops
- cinemas
- local coffee shops.

However, across all outlets many people said they had an indifferent or poor experience as opposed to an excellent experience. According to Capability Scotland's report, the two areas in which all service providers were failing were the provision of aids and the availability of information in a range of accessible formats (Capability Scotland, 2003a).

In another survey by Capability Scotland (2004), respondents had visited a range of shops in the past year, but results showed that disabled people were less likely than those who were carers or parents to go shopping. Supermarkets/food stores were the most popular shops. All the carers and parents, and over 90 per cent of disabled people, said that they had been to this type of shop in the past year. A significant finding was that out-of-town shopping was very popular with respondents: 77 per cent of them had been to an out-of-town shopping centre in the past year. The centres appealed across the age groups and had been visited by people with all types of impairment. The reasons for the popularity of out-of-town shopping among the respondents included easier access than in town centres because of the layout; shops being less crowded; and better disabled parking. Those people who preferred shopping in the city centres did so because of the range of shops available; the proximity to home; and familiarity with the shops.

The same survey found that 44 per cent of all respondents had bought goods online or over the Internet in the past year. Disabled people were only slightly less likely than carers or parents to have bought goods online: 38 per cent of disabled respondents had bought online in the last year. Respondents over the age of 54 were far less likely than younger respondents to have bought online. The main types of goods and services bought online were books, records and CDs, and holidays and travel goods.

Figure 5.1: Finding services very or fairly inconvenient, by adult population with any long-term illness or disability (percentage)



Source: Adapted from Scottish Household Survey 2001–02

Figure 5.1 indicates that, according to the Scottish Household Survey, people both with and without a disability considered that banks and public transport were very or fairly inconvenient. Almost double the number of people with a long-term illness or disability had difficulty accessing grocery/food shops and the post office, compared with non-disabled people (Scottish Executive, 2003d).

Disabled and non-disabled children are interested in a range of things from sport to drama, arts and crafts, going to parks and playgrounds, clubs, cinemas, bowling alleys or just hanging out with friends. A lack of access to social facilities was widely reported in a survey of disabled children and their parents (Connors and Stalker, 2002). Older children experienced difficulty accessing public transport and leisure spaces such as fast-food outlets.

Some of the barriers children encountered seemed to be based on the view that impairment was something that happened to adults rather than children, whose needs were often ignored. For example, one boy found that his local Shopmobility had no children's wheelchairs. The study recommended more social and leisure opportunities for disabled children, especially teenagers and those attending out-of-area schools. This finding has implications stretching far beyond service provision, and particularly for the commercial sector, since many young people wanted to be able to access the same leisure venues as their non-disabled peers.

In a report that looked at access to public services in Scotland using British Sign Language (BSL), Kyle et. al (2005) found that when deaf people met with service providers who could sign, their levels of satisfaction increased. Lack of interpreters was found to be a problem. Using automated machines was problematic because if anything went wrong people were expected to use voice intercoms to obtain help. Deaf people were found to be keen users of text messaging, and considered that this method of communication could be used to receive information from service providers.

5.2 Views from providers of goods and services

In a survey for the Department for Work and Pensions, nearly three-quarters of service providers said they had adjustments in place, or plans to assist disabled customers (Roberts et. al, 2003). Part 2 of the Disability Discrimination Act 1995 made it unlawful for employers covered by the Act to discriminate against employees or job applicants on the grounds of disability. Part 3 of the Act places specific requirements on the way goods, facilities or services are offered to disabled people, making it unlawful to treat disabled people less favourably than other people for a reason related to their impairment. Service providers who were aware of these provisions, and those with a policy for disabled customers, were more likely to have made, or to be planning to make, changes to accommodate disabled customers than those who were unaware of the legislation.

In a similar survey, 40 per cent of establishments covered by Part 3 of the Disability Discrimination Act reported having made adjustments for disabled customers or clients (Meager et. al, 2005). The most common reason for not making any adjustments was that no special arrangements or adjustments were required. Among establishments with customer contact on the premises, the most common types of adjustment made related to wheelchair or disability access to the premises (75 per cent). A smaller number introduced disability awareness training (37 per cent) and the production of large-print copies of documents (30 per cent). The benefits cited were customer satisfaction; an increased number of disabled customers; and improvements in external image and reputation. The study also found no evidence that those who had not made adjustments already, or who had made few, were planning to ‘catch up’ in the future.

In 2004, the Disability Rights Commission asked 200 Scottish businesses about their attitudes and awareness of their duties under Part 3 of the Disability Discrimination Act. Around three-quarters of the businesses surveyed indicated it was important their premises were accessible to disabled people. Businesses that had made changes to make their premises more accessible were most likely to install a ramp (57 per cent) or make doorways wider (44 per cent) (Disability Rights Commission, 2004b).

The specific problems that disabled people have in access to goods and services need to be considered alongside other potential difficulties such as availability and affordability. A study for the Joseph Rowntree Foundation found that about 1 in 14 of the population are excluded from four or more of a list of essential public and private services, and nearly 1 in

4 from two or more because the services are either unaffordable or unavailable. Non-availability of services is a bigger barrier than non-affordability (Gordon et. al, 2005).

5.3 Summary

Evidence from a variety of sources indicates that disabled people do have difficulties accessing mainstream goods and services. The 2003 Disability Awareness Survey found that almost 4 out of 10 people with mobility and sensory impairments said they have difficulty accessing goods and services. However, direct access needs to be considered alongside other potential difficulties such as availability and affordability. To harness the potential spending power of disabled people, providers of goods and services will need to consider how 'disability friendly' their premises are or could be in the future.

6 Health, wellbeing and independent living

This chapter focuses on health and wellbeing, and seeks to identify some key indicators of the differences in experience of health and support services between disabled and non-disabled groups.

6.1 Data issues

A key element to emerge from the review of evidence was the lack of Scottish data seeking to describe disabled people's experiences of health and support services at even the most basic level. This may be because the health professions tend to manage the care of disabled people by the impairment they present for treatment on any given occasion. The health services treat all users more or less as a set of symptoms to be managed or treated; they therefore do not record instances of particular conditions among disabled people. For example, data on heart disease do not seem to be available in such a way as to identify sufferers who are also impaired in another way. This makes it difficult to isolate and analyse the experience of users of healthcare services who are disabled, compared with those who are non-disabled. Most of the evidence that is available concerns the experience of those with learning disabilities and necessarily, therefore, much of what follows draws on that evidence.

A further difficulty arises in the tendency to combine the data for 'disability' and 'long-term illness'. Under the Disability Discrimination Act 1995, a limiting long-term illness serves to identify an individual as 'disabled', but we would argue that this will tend to cover up differences in experience across different disabled groups. For instance, a woman with a learning disability may also suffer from breast cancer, but the data routinely collected by health services did not allow us to identify a difference in the outcomes from cancer treatments between a woman with learning difficulties and another without. This may not seem important, until we consider that people with learning disabilities may be up to 58 times more likely to die before the age of 50 than other people (Disability Rights Commission, 1998). That being the case, we must ask whether there are quantifiable differences in the outcomes arising from particular ‘killers’ like cancer, and heart and respiratory diseases, that are due to other disabilities suffered by the presenting patients. It is not clear from this review that such data, which could be crucial in re-thinking services to address what Demos calls ‘disablism’, is currently available (Demos, 2004).

Finally, the absence of much Scotland-specific data has forced us to rely on evidence gathered elsewhere in the UK or on a UK-wide basis. Where possible we have identified the occasions where non-Scotland-specific data has been used. However, on the basis of the data that are available and the qualitative evidence provided by disabled people’s own descriptions of their experience of services, it is possible to identify some key issues.

6.2 Disabled people’s take-up of health services

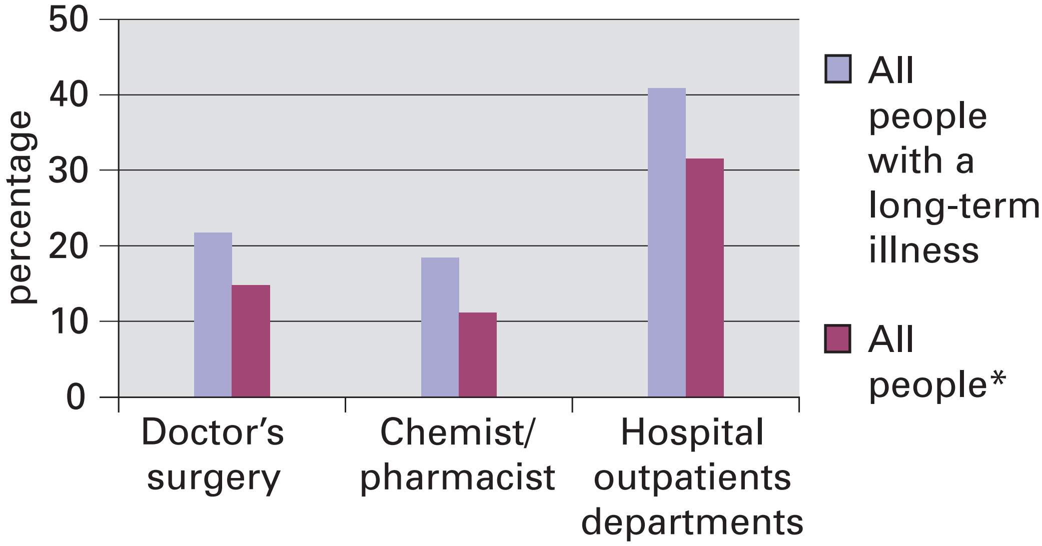
The most useful evidence available on disabled people’s participation in health and care services, excluding those services specifically provided for disabled people, is data on their take-up of screening and other appointments compared with take-up among non-disabled users. According to one study cited in a review of evidence (Valuing People Support Team, online), women with learning disabilities are between three and four times less likely to undergo cervical smear tests than the general population – 19 per cent for women with learning disabilities compared with 77 per cent for the general population. They are also significantly less likely to attend breast cancer examinations, or even be invited to attend mammography, than the whole population.

Meanwhile, people with learning disabilities show the same frequency of visits to their GPs as the general population, but are less likely to receive regular health checks. They also show an increased uptake of hospital-based medical and dental services compared with the general population, but a reduced uptake of surgical specialities. This latter evidence seems to support the Disability Rights Commission's claims of 'diagnostic overshadowing', where particular health problems are not addressed or are treated differently because of a patient's learning disability.

6.3 Experience of health services

The evidence also shows significant differences between disabled and non-disabled people's experiences of the services they access. One of the most commonly identified differences is in the experience of 'inconvenience' in accessing services. In the 2002–03 Scottish Household Survey, in a range of services, hospital outpatient departments were most commonly identified as inconvenient by disabled people, and were also the source of the biggest difference in experience between disabled people and all people. Hospital outpatient services were considered very or fairly inconvenient by 41 per cent of people with a long-term illness or disability, as opposed to 31 per cent of all people (Scottish Executive, 2003d). Their relative experiences of other healthcare-related services are shown in Figure 6.1 below, adapted from the same source.

Figure 6.1: Percentage finding health services very or fairly inconvenient, by adult population with any long-term illness or disability



* 'All people' means all 28,667 adults surveyed, including disabled people, people with a long-term illness and/or health problem, and non-disabled people.

Source: Scottish Executive (2003d)

However, an NOP survey of 500 disabled people (including 100 in Scotland), conducted for the Disability Rights Commission in 2003 (Chowdhury and Worley, 2003) reported that only 20 per cent of respondents GB-wide, and 24 per cent of Scottish respondents, mentioned 'difficulties' in the course of an appointment or visit to a hospital or clinic, although this was still the most commonly cited place where difficulties were experienced. The difference in experience between Scottish respondents and the GB-wide figure is noteworthy.

The same survey suggested that straightforward physical access to services remains the most fundamental problem facing disabled people. The factor that caused the most difficulty for disabled customers was heavy doors (reported by half of respondents), followed by steps at the entrance to a building (almost half).

Disabled people's own stories of their experiences of healthcare (and those of their families) are remarkably telling, and a number of different sources provided such stories (Disability Rights Commission, 2003a; Mencap, 2004; Morris, 2004). Clearly, it can be misleading to over-generalise on the basis of individual stories, but overall, our reading of these stories is that:

- The presence of impairment is perceived to impact strongly and negatively on the quality of treatment received for common conditions. For example, learning disabilities were commonly thought to have negatively affected diagnoses, with sometimes fatal consequences.
- Patients with an impairment felt that healthcare professionals did not make sufficient allowances for their impairments during their interactions. An example of this behaviour might be looking away from a hearing-impaired patient (to examine monitors or notes) while explaining the planned treatment, leading to unnecessary difficulties and frustration.
- Healthcare staff are often perceived to assume a profound level of disability without first trying to speak to an impaired patient. For instance, primary care staff might assume that a speech-impaired patient could not speak for themselves at all, or even fill in a registration form, without taking the time to engage with the patient.
- Information on healthcare services is often not made available in formats suitable for the full range of impairments among patients. Healthcare providers often fail to offer information or signage suitable for visually impaired people.

6.4 Health outcomes

Ultimately, the key test of healthcare services in assessing how well they meet the needs of disabled patients is whether there is any difference in health outcomes between disabled and non-disabled people. The evidence below speaks for itself, as it seems clear that there is indeed a significant difference in outcomes between disabled and non-disabled groups (Valuing People Support Team, online).

- As already noted, there is evidence that people with learning difficulties are at a significantly increased risk of early death compared with the general population, although life expectancy among this group has been improving steadily.
- Although the incidence of deaths from cancer is lower among people with learning disabilities than in the general population, the incidence of cancer among people with learning disabilities is rapidly increasing as longevity improves. This contrasts badly with falling rates of cancer mortality among other groups, and highlights the dangers in the poor participation rates of women with learning disabilities in cancer screening programmes.
- Respiratory disease is a cause of death among learning disabled people as much as three times more often than for the general population (46–52 per cent for people with learning disabilities; 15–17 per cent for the general population).
- People with learning disabilities are significantly more likely to have a visual impairment, but are unlikely to be assessed for visual impairments, because staff attribute lower levels of functioning to the person’s learning disability.
- 36.5 per cent of adults with learning disabilities and 80 per cent of adults with Down’s syndrome have unhealthy

teeth and gums. Adults with learning disabilities who live with their families have more untreated decay and poorer oral hygiene.

6.5 Independent living

The Scottish Household Survey 2002 reported disability increasing with age: 40 per cent of people aged 65 years or over reported a disability or long-term illness. In 12 per cent of households there are one or more people who need regular help or care because they are sick, disabled or elderly. This figure rises to 22 per cent for single pensioners (Carers in Scotland, website).

One of the primary targets for policy-makers is to support older people to live independently in their communities where this is appropriate (Scottish Executive, 1999b; 2004i). At present only 4 per cent of people over the age of 65 are in care homes, of whom over half are aged 85 or over (Scottish Executive, 2003c). There has also been an increase in sheltered housing, rising from 8,700 in 1980 to 36,700 in 1999 (Scottish Executive, 2003c), and the relative fall in the number of residential places per thousand of the population aged 75 and over (which dropped from 54 to 47 over the same period) implies that there are increased opportunities for older people to live independently. The number of hours of service provided to community care home users has increased by 25 per cent since 1998, and 83 per cent of those receiving a home care service in Scotland are aged 65 or over (Age Concern, 2001).

The public resources used to support people in the community are supplemented by care provided by family members, friends and neighbours, as well as through community and voluntary sector organisations. Living independently and maintaining a good quality of life require a broader social responsibility than straightforward social care. Reported disability increases with age, therefore as the Scottish population ages, it will be important to consider what support, in addition to social care, will be required to help people live independently and maintain a good quality of life. Independent living has been described by Demos as being about making independent decisions about how to live, empowering and involving individuals about the choices open to them, and enabling them to put their choices into practice (Demos, 2005).

Direct payments are deemed to be one way of offering choices. Since April 2005 local authorities have had a duty to offer direct payments to everyone aged 65 and over who is assessed as needing community care services due to infirmity or old age (Scottish Executive Health Department, 2005). In terms of the longer-term implications we need to understand the potential impact of this approach as access broadens. Some examples include:

- Who will support older people as they make choices about their personal support?
- Where will trusted intermediaries come from and who will pay (or volunteer) to ensure this is available?
- Will people find themselves paying for assistance where once neighbours or friends helped out?

The intended outcomes of giving disabled people more power and control over their support arrangements are important to people's independence and sense of control over their lives. It is important to ensure that choice comes with an effectively resourced support infrastructure so that it does not disempower the people it is intended to support.

The group most likely to be involved in unpaid caring is the 50–59 age group, in which 10 per cent of men and 14 per cent of women provide up to 20 hours unpaid care a week. Women are more likely than men to be providing the bulk of care when in their fifties but less likely in their late eighties. Providing care has an impact on the personal lives, health and relationships of carers, and poor physical health is more common among those who provide over 50 hours of care in a week (Scottish Executive, 2003d). For example, Carers Scotland estimate that people providing high levels of care are twice as likely to be permanently sick or disabled (Carers Scotland, website).

Older women are more likely to live alone than men. Over the age of 85, 71 per cent of women at home live alone compared with 42 per cent of men at the same age (Office for National Statistics, 2004b). For older people, social isolation can lead to depression, loneliness and anxiety, which in turn can prevent them from interacting with their local community and accessing the services they need (Scottish Executive, 2005a).

Provision of day care services is one route to ensuring that social interaction and activities are provided (see Table 6.1). There is a mixture of provision. Local authorities run 65 per cent of the centres, providing 74 per cent of the places. The voluntary sector runs 22 per cent of the centres and provides 22 per cent of the places. The private sector runs 9 per cent of the centres, providing 4 per cent of the places (Scottish Executive, 2004a). Private sector provision is noticeably higher for older people. Only one of the centres for people with physical needs and one for those facing mental health problems is run by the private sector. With the exception of centres for those with learning difficulties the remaining centres have more users than places.

Table 6.1: Registered day care services by client group and sector

Intended client group	Number of centres	Number of places	Number of users*
Older people	400	7,650	11,807
People with learning disabilities	171	8,090	7,372
Physically disabled people	43	1,623	2,029
People with mental health problems	19	505	509
Other client groups	24	725	930
Total	657	18,593	22,647

* User figures are for the week ending 31 March 2004

Source: Day Care Services Census Return D1-B (Scottish Executive, 2004a)

Disabled adults are more likely to have a home help (19 per cent) than adults with a long-term illness (11 per cent). Differences also exist by gender, with more women having a home help than men. The likelihood of having a home help also increases with age: adults aged 75 and over are significantly more likely to have a home help than those in younger age groups.

6.6 Summary

This review of evidence demonstrated a lack of Scottish data that seeks to describe disabled people's experiences of health and support services at even the most basic level. This may be because health professions tend to manage the care of disabled people by the impairment they present for treatment on any given occasion; they therefore do not record instances of particular conditions among disabled people. A further difficulty arises in the tendency to combine the data for disability and long-term illness. Most of the evidence that is available concerns the experience of those with learning disabilities.

Although straightforward physical access to services remains a problem facing disabled people, information on healthcare services is often not made available in suitable formats for a range of impairments.

A number of sources found that patients with an impairment felt that healthcare professionals did not make sufficient allowance for their impairments during interactions. The presence of impairment is perceived to impact strongly and negatively on the quality of treatment received for common conditions, and there would appear to be a significant difference in outcomes between disabled and non-disabled groups.

7 Education and learning

> Learning can provide an important route out of poverty for individuals, their families and their communities. (Scottish Executive, 2003f)

Equality for disabled people in education and learning is important in determining the opportunities open to them in the future. In this chapter we compare the experiences and outcomes of education and learning for disabled people and non-disabled people.

7.1 Legislation

There is legislation already in place to promote the rights of disabled people within education structures. For instance:

- the Special Educational Needs and Disability Act 2001 (SENDA) obliges schools not to discriminate against children with special educational needs
- the Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002 (DSPERA) calls for schools to put in place strategies to improve the accessibility of their institutions for pupils with disabilities and to ensure that the curriculum is fully open to the participation of all students
- the Education (Additional Support for Learning) (Scotland) Act 2004 ensures that children with the most complex additional support needs will be supported in their education by a co-ordinated support plan. A co-ordinated support plan outlines why the child requires the additional support, the desired educational objectives for the child's teaching, what needs to be done to achieve these objectives, and who will be responsible for their realisation. Each plan will be tailored to the child's individual abilities and strengths, thus informing the aims and the curriculum. Parents and guardians will have the right to inspect the plan. This system will

gradually replace the earlier version, the record of needs, which was used in the past to outline the provisions a child with additional needs would require. Children who already have a record of needs will be assumed to have additional support needs and will be assessed to determine whether they require a co-ordinated support plan.

7.2 Compulsory education

The national priorities in school education, as approved by the Scottish Parliament in December 2000, are defined under the following headings:

- achievement and attainment
- framework for learning
- inclusion and equality
- values and citizenship
- learning for life.

Participation in compulsory education

Scottish Executive data show that the number of pupils with a record of needs[4] in publicly funded primary schools fell slightly between 2001 and 2002 (Scottish Executive, 2002b). The overall number is just over 1 per cent of the total school population (see Table 7.1).

Table 7.1: Number of pupils with a record of needs in publicly funded primary schools

	September 2001		September 2002	
	Total number of pupils	Number of pupils with record of needs	Total number of pupils	Number of pupils with record of needs
Scotland	420,521	4,303	413,713	4,165

Source: Scottish Executive (2002b)

A large proportion of students with additional support needs are educated in mainstream schools. In 2003, 73 per cent of the 25,800 pupils with additional support needs were taught in the mainstream sector. At the same time, 7,600 pupils received their education in special schools (Scottish Executive, 2004c).

Including pupils with additional support needs into a mainstream school environment is now commonplace in Scotland. One in six local authorities do not have any dedicated, stand-alone, state sector additional support needs school (Sunday Herald, 2005).

A study for Barnardos found that disabled children/pupils benefit educationally from inclusive education, while non-disabled children/pupils also do as well or better within an inclusive setting (Sebba and Sachdev, 1997). Peer acceptance is seen in an inclusive setting, although more so in primary than in secondary education. The Standards in Scotland's Schools Act 2000 sets out expectations for schools and education authorities in relation to an individual child's right to education, and their role in providing for it. The Act presumes that the education of all pupils will normally be provided in a mainstream school unless exceptional circumstances apply. Explicit within an inclusive education system is that schools offer a wide range of different learning opportunities, which are adapted and tailored to meet the needs of particular individuals in ways which engage and motivate them. Specialist provision for pupils with special needs, including social, emotional and behavioural needs, has an important role to play (Scottish Executive, 2002c).

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[4] The record of needs (RON) is a means of assessing, planning and delivering provision for a child with special educational needs.

Experience of compulsory education

There were 134 exclusions per thousand pupils in special schools in 2003–04 compared with an average rate of 105 exclusions per thousand pupils in Scottish secondary schools and 11 per thousand pupils in primary schools (Scottish Executive, 2004f).

A Disability Rights Commission survey (2002–03) in England and Wales found that 45 per cent of young people interviewed said that they had experienced problems at school for reasons related to their impairment, and 38 per cent of respondents said that they had been bullied (Disability Rights Commission, 2003b). In one Scottish survey almost half the children reported being bullied, and this occurred in all types of school setting (Connors and Stalker, 2002). A few also said they had been bullied within or near their home. All of these children were attending schools outside their local community. Most children dealt effectively with a single incident of bullying themselves but, for a few, being bullied was a daily occurrence.

Focus groups with disabled young people uncovered a limiting of aspiration linked to age. Findings suggested that at the age of 12, children's aspirations were very much in line with non-disabled peers: they all wanted to do different things when they grow up. By the age of 17, they appeared to have adopted much more narrow expectations of the working world, with many seeking employment in information technology. The report also suggested that many disabled children have few friends outside school, and as teenagers they spend disproportionate amounts of their time in adult company (Capability Scotland, 2003b).

In Scotland in 2005 the number of schoolchildren with autism has risen to more than 3,000 for the first time, a rise of 820 since 1998. Of the 3,000 children registered as having autism, the vast majority, almost 2,700, are boys (Scotsman, 2005). The National Autistic Society found that 72 per cent of UK schools are dissatisfied with levels of training for teachers in relation to autism. Only 22 per cent of teachers had received autism-specific training (Barnard et. al, undated).

Outcomes from compulsory education

Data for 2003–04 show that 18 per cent of Scottish pupils with a record of needs left school without attaining national qualifications at Level 3 or above, compared with 3.5 per cent of pupils with no record of needs (Scottish Executive, 2005c). At the same time, only 2.9 per cent of pupils with a record of needs left school with 1–2 qualifications at Scottish Credit and Qualifications Framework (SCQF) Level 7, compared with 12 per cent of pupils without a record of needs.

7.3 Post compulsory education

Promoting participation in education and learning is a primary target for the Scottish Executive. The development of the lifelong learning strategy focuses on post-compulsory opportunities, based on principles of social inclusion and equality. Realising the vision in the strategy depends on achieving a number of goals. These include a Scotland where:

- people have the confidence, enterprise, knowledge, creativity and skills they need to participate in economic, social and civic life
- people demand and providers deliver a high quality learning experience
- people's knowledge and skills are recognised, used and developed to best effect in their workplace
- people are given the information, guidance and support they need to make effective learning decisions and transitions
- people have the chance to learn, irrespective of their background or current personal circumstances.

Lifelong learning provides scope to move beyond school and identify the activities that are available to disabled people to pursue personal development opportunities through learning.

Although the law and previous educational experiences may drive transitions, they are also the subject of powerful influences, including the views and beliefs of parents; demography; socio-economic factors; peer group preferences; and local opportunities for education, training and work (University of London, online). In making the transition from school to college good practice has been identified, such as schools and colleges working closely together, and with other agencies, to enable young people to make decisions about their future and move into college with the support that they need (Scottish Executive, 2002d). Collaborative approaches are necessary to find the best pathways for individual young people. Skill Scotland suggests that improving transitions between different parts of lifelong learning is particularly important for learners who have additional support needs (Skill Scotland, 2004). These learners are often delayed, disadvantaged or prevented from moving from one institution to another because of difficulties in getting the information and advice, the support and adjustments, and the flexibility and accessibility which they need.

Additional funding provided by the Scottish Executive for disabled students in further education colleges led to a rapid expansion of further education courses, but often students with learning difficulties tend to be segregated from mainstream provision (Riddell et. al, 2001). A review of services for people with learning disabilities recommended the expansion of the range of short courses provided in day centres by further education colleges (Scottish Executive, 2003a). Its recommendations also included:

- a greater range of employment opportunities

- more children educated in mainstream schools
- most people with learning disabilities having access to mainstream health, social care, and education and employment services
- greater community participation by people with learning disabilities.

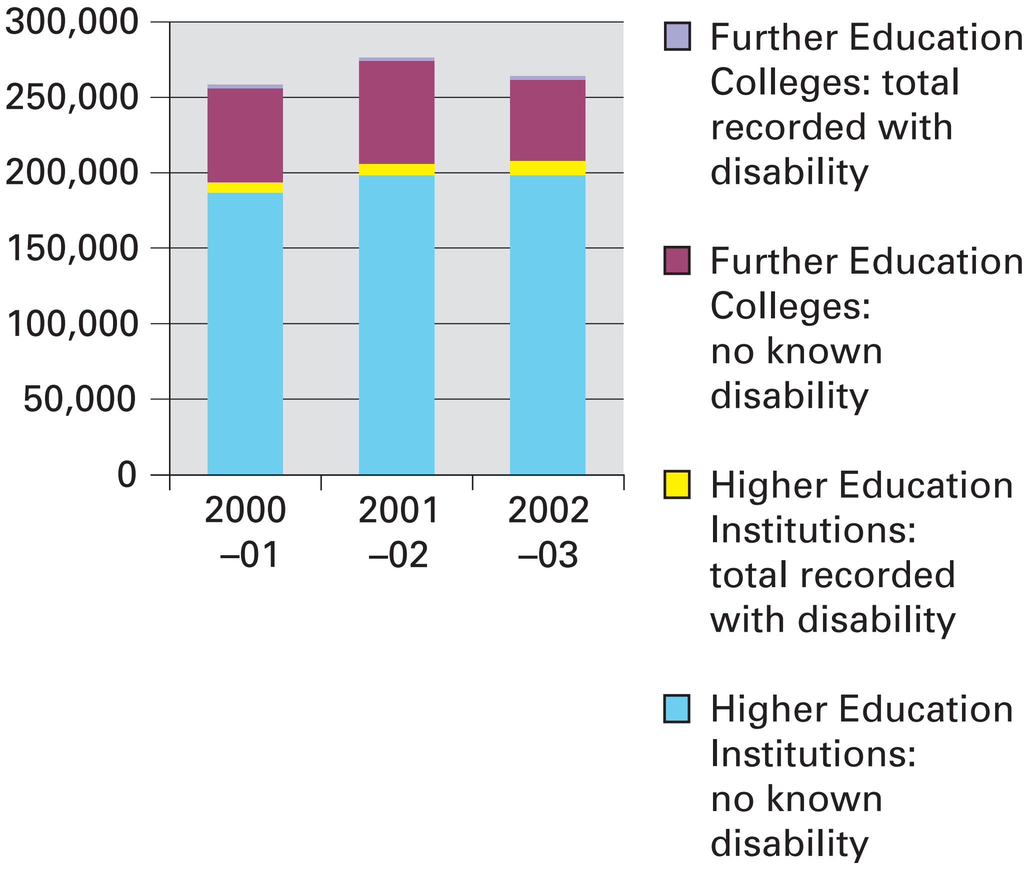
The Beattie report looked at post-school provision for young people with additional support needs (Scottish Executive, 1999a). The Committee's recommendations included the appointment of a key worker for each young person to support them during their transitional period, and establishing area support groups to oversee key worker activity and co-ordinate the work of different agencies. Around 13 multi-agency projects have been established across Scotland providing key worker support for young people. There are 120 key workers in place, drawn from different backgrounds including careers, social work, community education and the voluntary sector (Scottish Executive, 2005b).

Participation in higher and further education

The number of disabled students in higher education between 2000 and 2003 has increased slightly. Data for 2002–03 show that 4.4 per cent of students in higher education had a recorded disability, accounting for 11,700 students (Scottish Executive, 2004b). This is an increase from 2000–01 when 3.5 per cent of students (9,100) had a recorded disability.

The Higher Education Statistics Agency's assessment figures for 2002–03 illustrate the numbers of students in receipt of Disabled Student's Allowance within Scotland's universities. Although not all disabled people within higher education may actually claim Disabled Student's Allowance, the figures nevertheless give an indication of the participation of disabled people throughout the Scottish higher education system and allow comparisons to be made across the various academic institutions.

Figure 7.1: Disabled students in higher education in Scotland: 2000–01 to 2002–03



Source: Scottish Executive (2004b)

Within further education in 2003–04, there was a total of 467,000 enrolments at Scotland's 45 colleges, equating to about 370,000 students. Of these, 34,000 enrolments (24,000 students) declared a disability (7.2 per cent of enrolments and 6.6 per cent of students) (Scottish Funding Council, 2005).

Outcomes from further and higher education

Data from the Scottish Further Education Funding Council (SCEFC), shown in Table 7.3, show the number of further education students awarded a Higher National Diploma (HND) or equivalent qualification in 2003–04.

Table 7.2: Participation of students in higher education who are in receipt of DSA: all undergraduate students 2002–03

	Entrants	Entrants claiming DSA (number)	Entrants claiming DSA (%)
The University of Aberdeen	8,625	140	1.6
University of Abertay Dundee	3,115	75	2.4
Bell College	740	15	2.0
The University of Dundee	5,870	130	2.2
Edinburgh College of Art	1,085	95	8.9
The University of Edinburgh	13,800	365	2.7
Glasgow Caledonian University	8,715	85	1.0
Glasgow School of Art	1,045	150	14.2
The University of Glasgow	13,895	185	1.3
Heriot-Watt University	4,145	95	2.3
Napier University	5,805	25	0.5
The University of Paisley	4,385	135	3.1
Queen Margaret University College, Edinburgh	2,435	80	3.3
The Robert Gordon University	4,850	105	2.1
The Royal Scottish Academy of Music and Drama	510	30	5.9
The University of St Andrews	4,330	150	3.4
The University of Stirling	4,685	110	2.4
The University of Strathclyde	10,935	180	1.6
UHI Millennium Institute	570	0	0.2
Total Scotland	99,535	2,155	2.2

Source: HESA

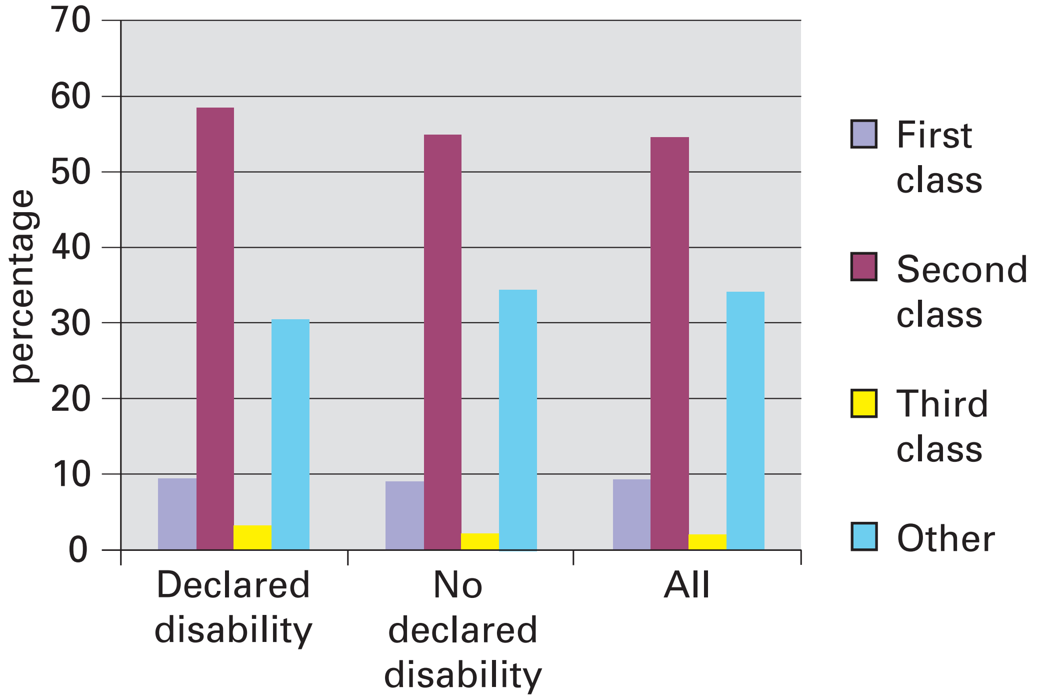
Table 7.3: Analysis of further education awards for year 2003–04

Candidate	Number who gained HND or equivalent
No known disability	14,057
Dyslexia	332
Blind/are partially sighted	28
Deaf/have a hearing impairment	42
Wheelchair user/have mobility difficulties	42
Mental health difficulties	43
An unseen disability, eg diabetes, epilepsy, asthma	228
Multiple disabilities	20
A disability not listed above	96
Information refused/not known	2,003
Total	16,891

Source: Infact Database, SFEFC
Source: Disability Rights Commission (2001)

Despite differences in participation rates, students with disabilities in Scotland perform on a par with, or outperform, non-disabled students. On average, as Figure 7.2 shows, students with a declared disability received slightly proportionately higher levels of first-class and second-class degrees than students who did not declare a disability (Scottish Executive, 2004c).

Figure 7.2: First degree higher education graduates from higher education institutions and further education colleges in Scotland, by disability status and degree class, 2001–02



Source: Scottish Executive (2004c)

Nonetheless, around 58 per cent of disabled people have no qualifications whatsoever, compared with only 24 per cent of non-disabled people (Disability Rights Commission, 2004a). In 2001–02, only 8 per cent of disabled people had a degree qualification, compared with 17 per cent of people with no known disabilities (Office for National Statistics, 2002).

7.4 Learning in communities

> The location of learning is extremely important; often more so than its actual focus. This is due not only to practical but to psychological and cultural factors. In some areas it is found that people are very reluctant to participate in activities outside their families and local environment. (McGivney, 2000)

Community-based learning provision involves a diverse group of education and learning providers. It can be focused on:

- developing skills and knowledge
- learning skills for employment or for volunteering
- increasing understanding of issues and needs in a community
- supporting community involvement in decision-making processes.

Community learning opportunities are provided to support personal development, community capacity building and accessing resources at community level (Scottish Executive, 1998). Community learning and development also aims to support participation at community level, especially around community planning.

Provision of learning opportunities in literacy and numeracy identified the importance of focusing on priority groups. These groups included people living on low incomes, people living in disadvantaged areas, people with limited initial education, and people with health problems and disabilities.

There are a number of providers involved in community learning and training, for example local authorities through community learning and development and voluntary sector organisations. We were unable to identify single or easy-to-access multiple sources of information on the participation and outcomes of disabled people.

7.5 Summary

Research findings suggest that young disabled people fare less well than their non-disabled peers in achieving outcomes from education and learning. Transitions between primary and secondary schooling and into further or higher education are important for all children, but particularly important for disabled children and young people. Progression is about personal development and confidence-building alongside academic progress in educational or vocational skills. For some young people, transitions at the age of 16 can lead to a more independent life. For others, they can mean greater dependency if they are unable to move into further or higher education, community learning or work experience.

The overall outcome from education and learning serves a variety of purposes such as personal fulfilment and economic and social inclusion. It is important to ensure that experiences of education are inclusive and equip young people with the skills required to be active participants in work and in other aspects of their daily lives.

8 Work and worklessness

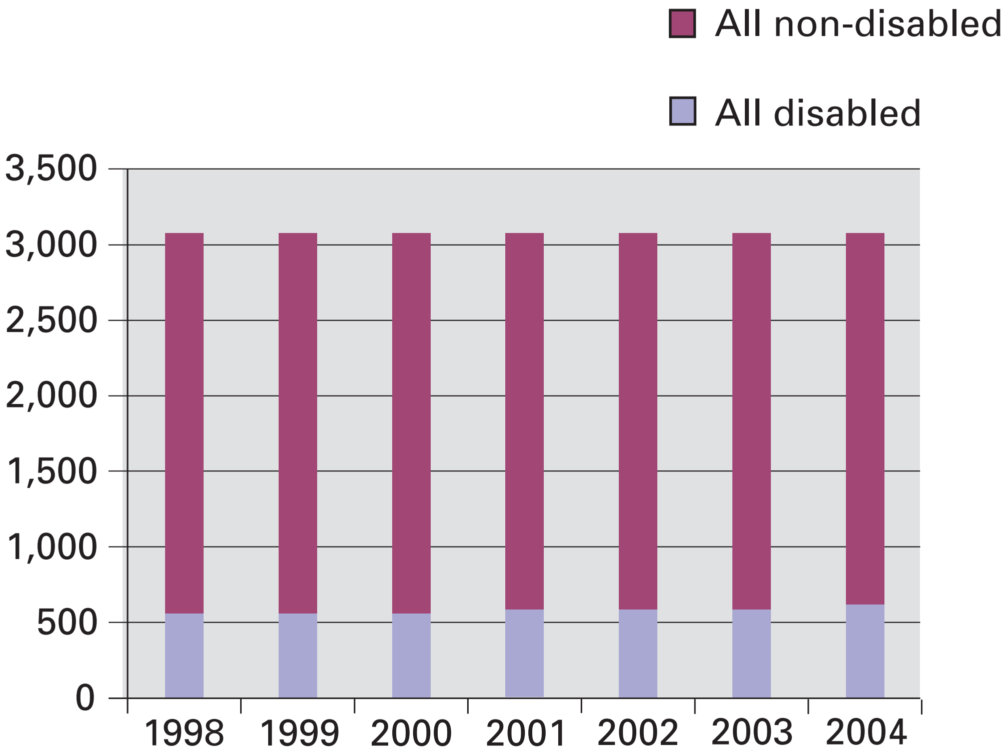
> By 2025, disabled people living in Britain should not face extra barriers relative to non-disabled people to fulfilling their potential in work. (National Employment Panel, 2005)

Work can play a positive role in the lives of disabled people by providing an income; offering a sense of self-worth, achievement and status; and increasing social contact and building social capital. Employment rates in the UK and Scotland are high by OECD standards. However, despite efforts by a range of stakeholders to open up employment opportunities (both through legislation and by promoting good practice) disabled people proportionally make up less of the working population than those identified as non-disabled. For example, the Department for Work and Pensions has introduced a series of measures to help disabled people into work, including:

- New Deal for Disabled People
- local disability service teams in job centres to help disabled people obtain and keep jobs
- Access to Work, providing support for disabled people in participating in mainstream employment.

8.1 Participation in the labour market

Figure 8.1: Disabled population in Scotland of working age, Spring 1998–Spring 2004 (thousands)



Source: Disability Rights Commission (2004e)

Figure 8.1 shows that between 1998 and 2004 the number of disabled people of working age has remained fairly constant, rising by 69,000, while the number of non-disabled people of working age has reduced by 63,000.

8.2 Disabled people's experience of the labour market

The Scottish Household Survey 2003 found that of those disabled people who were in employment, 87 per cent were employees, compared with 90 per cent of the non-disabled population (Scottish Executive, 2004c). No significant difference was identified between the proportions of disabled and non-disabled people who were self-employed. Full-time working was slightly more prevalent among the non-disabled population (76 per cent compared with 71 per cent of disabled people), whereas part-time working was more common among the disabled (28 per cent compared with 24 per cent). Research findings indicated that of those with a limiting long-term illness, the majority of people in both full-time and part-time employment live in large urban areas, rather than smaller more remote towns (Riddell et. al, 2005; see Table 8.1).

Employment rates for disabled people (45.9 per cent) and non-disabled people (81.7 per cent) suggest it is more difficult for disabled people to find suitable employment. UK research by Scope found that disabled people made an average of two and half times as many job applications as non-disabled people and yet got fewer job offers (Scope, 2003). More than 80 per cent of disabled respondents felt that fear of the unknown – the fact that in their view most employers do not know a disabled person and have not worked with a disabled person before – prevents employers taking on disabled employees. Almost 80 per cent of disabled people thought that the assumption that disabled people need more support from their colleagues and managers prevents employers employing disabled people. Almost 40 per cent of disabled people thought that negative staff attitudes were a barrier to finding employment. It can be assumed that disabled people in Scotland face similar difficulties.

The difficulties can be more extreme for those with multiple disadvantages. A study of people using supported employment services undertaken by the Scottish Human Services Trust (Weston, 2002) identified that 'people with complex needs found it easiest to choose a job when other people and support services believed they could work, and they had realistic and positive expectations of what work would be like'. Once in work all the participants worked part time. The range of employment opportunities on offer, location and their own skills and experience affected their

Table 8.1: Economic activity among working age people with a limiting long-term illness (LLTI) by Scottish Household Survey urban/rural classification (frequency)

	Large urban areas (000s)	Other urban areas (000s)	Accessible small towns	Remote small towns	Accessible rural	Remote rural
All people with LLTI	209	144	46,783	11,588	55,524	22,588
Economically active:	56	45	15,824	4,025	20,730	9,243
Employed:	46	38	13,596	3,375	18,369	8,091
Part-time	12	10	3,744	1,088	4,963	2,505
Full-time	34	28	9,852	2,287	13,406	5,586
Unemployed	8	6	1,883	565	1,957	1,021
Full-time student	2	1	345	85	404	131
Economically inactive:	153	99	30,959	7,563	34,794	13,345
Retired	8	7	2,406	570	3,128	1,440
Student	5	3	855	198	1,198	375
Looking after home/family	15	10	3,350	767	3,934	1,538
Permanently sick/disabled	103	67	20,756	5,025	22,436	8,449
Other	22	12	3,592	1,003	4,098	1,543

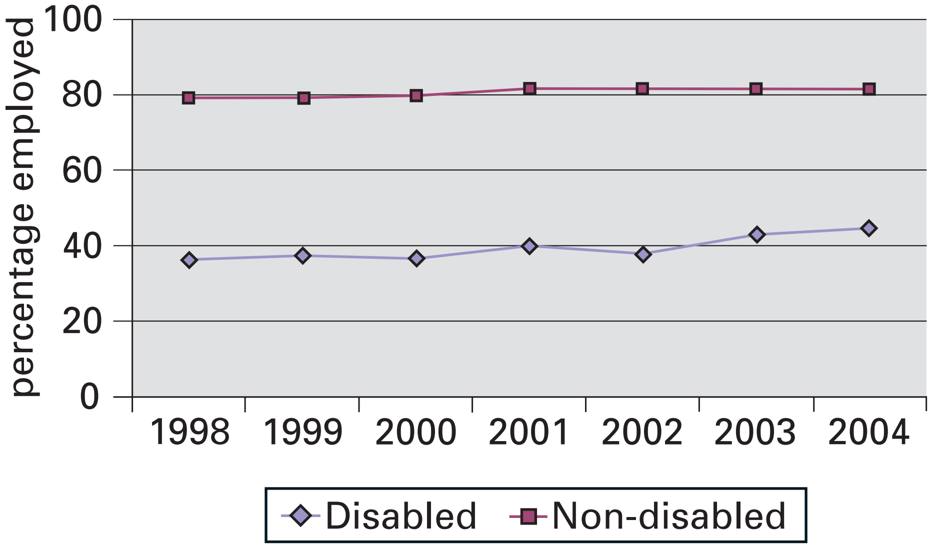
Source: Riddell et. al (2005)

choices of employment. Successful support was described by the researcher as person-centred, designed with awareness that it may change and based on good communication between key stakeholders.

When surveyed on behalf of the Department for Work and Pensions, 94 per cent of employers reported that their workplace always sought to recruit the best person for the job, regardless of any disability (Roberts et. al, 2003). Yet many employers felt that taking on a disabled person is a major risk for an employer (33 per cent), and that their workplace would find it difficult to retain an employee who became disabled (47 per cent).

8.3 Employment outcomes

Figure 8.2: Employment rates for disabled and non-disabled people in Scotland, Spring 1998–Spring 2004 (percentage)



Source: Centre for Economic and Social Inclusion (2005)

Figure 8.2 shows that between 1998 and 2004 there was a rise of around 10 per cent in employment rates for disabled people in Scotland, compared with a smaller rise of just over 2 per cent for non-disabled people (Centre for Economic and Social Inclusion (CESI), 2005). The employment rate for non-disabled people started from a much higher base; more than double that for disabled people. Although there were around 300,000 disabled people in employment in 2004, the figures show that disabled people had much lower employment rates than the non-disabled population.

Table 8.2: Estimated number of working age people in public sector employment, Scotland, Spring 1998 – Spring 2003 (thousands, not seasonally adjusted)

	1998	1999	2000	2001	2002	2003
Women:						
Disabled	28	43	32	43	46	47
Non-disabled	333	321	358	348	348	357
Total	361	364	390	391	394	404
Men:						
Disabled	27	24	22	32	23	29
Non-disabled	227	204	211	204	215	203
Total	254	228	233	236	238	232
All:						
Disabled	55	67	54	74	70	77
Non-disabled	560	525	569	552	563	560
Total	615	592	623	626	633	637

Source: Hirst et. al (2004)

There has been a rise of just over 60 per cent in the number of disabled women, but a reduction in the number of disabled men working in the public sector in Scotland between 1998 and 2003. This pattern is also to be found among non-disabled employees, where the number of women has also increased, with a corresponding reduction in the number of men. Figures show that just over 12 per cent of employees in the public sector are disabled (see Table 8.2)

We know that many people acquire a disability as a result of accident or injury, in adulthood.

> On becoming disabled the effect on employment status varies widely by severity of impairment. 84 per cent of people with the least complex impairments retain their employment, while just over half of those with multiple impairments do so. Within a year of becoming disabled around one in three single adults who were in employment have left employment, as have one in five individuals in two-adult households. (Burchardt, 2003)

Working life affects us in different ways. Results from the largest study of ageing conducted in Britain[5] were published at the end of 2003, and they make sobering reading (Institute for Fiscal Studies and University College London, 2003). The study found that manual workers in their fifties tend to suffer health conditions associated with old age around 15 years earlier than those in professional and managerial occupations (Briggs, 2003). The Scottish Executive has also found that the incidence of limiting long-term illness showed a steep increase for men in their sixties, while a comparable increase for women was not seen until their seventies (Scottish Executive, 2003e).

This ‘early ageing’ effect, reflected in routine and manual male workers in their fifties being twice as likely to have a limiting long-term illness as men in professional jobs, spanned various types of physical and mental ill health and was more true for men than women. Professor Sir Michael Marmot, co-author of the report, concluded that the level of impairment among relatively young manual workers was surprisingly high. This reflects to some extent the more physically demanding and risky nature of some jobs in

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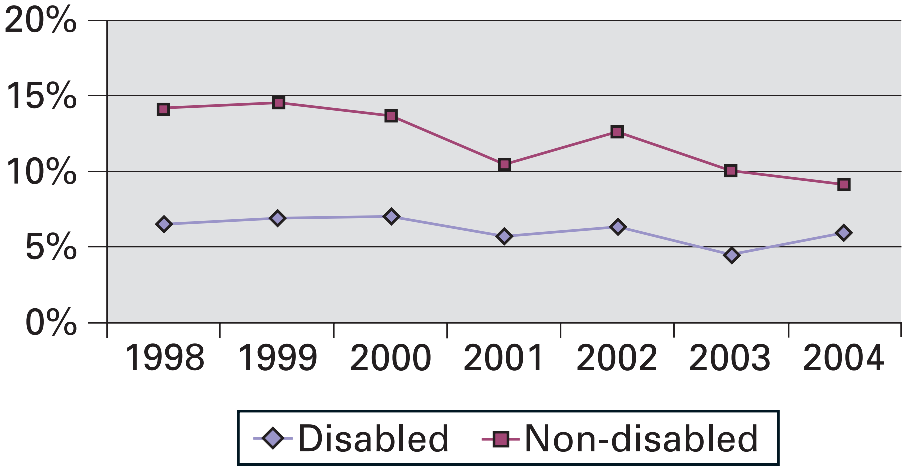
[5] By University College London, the Institute for Fiscal Studies and the National Centre for Social Research, based on data for more than 12,000 employees aged over 50 (England only).

construction, manufacturing, agriculture and even hi-tech factory working. The consequences for policy and practice reach far beyond the current remit of the Health and Safety Executive. A huge agenda for action needs to focus upon how the world of work can change to promote healthy ageing.

8.4 Unemployment and benefits

Figure 8.3 below shows that between 1998 and 2004 the unemployment rate dropped for both disabled and non-disabled people in Scotland. However, the gap is larger for the non-disabled group at over 5 per cent compared with just over 1 per cent for the disabled group.

Figure 8.3: Unemployment rates for disabled and non-disabled people in Scotland, Spring 1998 – Spring 2004 (percentage)



Source: Disability Rights Commission (2004e)

Table 8.3: Number of claimants of Incapacity Benefit and Severe Disablement Allowance in Scotland (thousands)

1998	1999	2000	2001	2002	2003
294.8	281.5	282.2	288.2	285.6	289.4

Source: Department for Work and Pensions (2002b)

There are now more people claiming benefit on the grounds of incapacity than on the grounds of unemployment and lone parenthood combined. More young people and more women are now claiming Incapacity Benefit, and the number of people claiming Incapacity Benefit because of mental health problems has doubled since 1995 (Social Exclusion Unit, 2004). However, there has also been a small but steady reduction in Incapacity and Severe Disablement Allowance claimants since 1998, of 5,400 (Table 8.3).

Between 2000 and November 2004 the number of people in receipt of Disability Living Allowance increased by 58,200 (Table 8.4).

Table 8.4: Number of people in receipt of Disability Living Allowance In Scotland (2000–04) (thousands)

Allowances 2000	Allowances May 2003	Allowances November 2004
237.3	277.7	295.5

Source: Department for Work and Pensions Statistical Summaries 2003, 2004; Scottish Executive Scottish Statistics, 2001

The number of people of working age claiming key benefits decreased from 562,800 in 2001 to 536,800 in 2004 (Scottish Executive, 2004g). However, it is common for people to claim multiple benefits. In August 2003 it was estimated that over 500,000 people of working age in Scotland were claiming one or more key disability-related benefits (Riddell et. al, 2005):

- 185,200 were in receipt of Incapacity Benefit
- 281,200 were in receipt of Disability Living Allowance
- 133,800 received Attendance Allowance
- 36,400 received Severe Disablement Allowance
- 40,600 received Carers Allowance.

Although programmes such as New Deal for Disabled People are relatively recent, such initiatives would need to reach a much larger number of people to make a significant impact in moving many more disabled people into employment. As Table 8.5 shows, overall results up to November 2005 indicate out of almost 19,000 starts around one in three secured a positive outcome.

Table 8.5: New Deal for Disabled People Summary to November 2005 (Scotland)

Starts*	Current Participants*	Outcomes**
18,770	10,960	11,890

Source: Department for Work and Pensions (November 2005)

* Starts and participant numbers relate to registrations with NDDP Job Brokers

** Jobs include both Job Broker and NDDP Jobcentre Plus jobs

8.5 Summary

Between 1998 and 2004 there was a rise of almost 10 per cent in employment rates for disabled people in Scotland. If we were prepared to abandon our prejudices towards disabled people, and adopt a genuine commitment to promoting equality in the workplace, we could bring thousands more people into the workforce who have never had that opportunity before, as well as attracting back a proportion of former workers parked on Incapacity Benefit. This would simultaneously promote social justice and boost the economy. This approach would only work if we were prepared to change our mental model of work, from one where full time (9–5) dominates to one where flexible working was truly accessible and available to all employees. At present availability according to formal policy and accessibility in practice are very different.

Government employment services and other measures designed to help disadvantaged groups in the labour market can help 'level the playing field' to assist disabled people compete on better terms than at present. It is not just a matter of ensuring that a disadvantaged group gets extra assistance or does not face discrimination: important as these things may be, progress and sustainability require a productive partnership between government, employers and employees.

There are clear signs that the 'healthy working lives' agenda will become more prominent in thinking and action within policy circles. Problems with health and stress can build up over the course of a working life and eventually lead employees to feel that they have no option but to stop work for the sake of their health, or are forced to do so by their employers. To address this, policy-makers and employers need to think about health in work as a process that needs to be better managed.

9 Income and living standards

There are a number of factors that can impact on financial circumstances, such as educational attainment, earning potential, types of benefits, location and household expenditure. Income is an important determinant of overall quality of life. In this chapter we look at the income and living standards of disabled people compared with those of non-disabled people.

9.1 Experience of disabled and non-disabled people

The Disability Rights Commission found that at £9.36 per hour, the average gross hourly pay of disabled employees is about 10 per cent less than that of non-disabled employees (£10.39 per hour). Separate figures were not available for men and women (Disability Rights Commission, 2004e).

The difference in pay is borne out by the Labour Force Survey 2003, which found the average gross weekly pay in the main job for those disabled people in full-time employment is around 90 per cent of the pay for a non-disabled person. Again no figures were available to make a comparison between men and women (Scottish Executive, 2004c) (see Table 9.1).

Table 9.1: Average gross weekly pay (£) in main job by disability status, 2003

All	Non-disabled	Disabled
413.4	417.7	383.5

Source: Labour Force Survey 2003

Pay is part of the equation. However, overall household income is also important. Almost one-third of all Scottish households have an annual income of £10,000 or less. However, this proportion is considerably higher for households containing members who are disabled or have a long-term illness, across most household types. At the higher end of the income scale, almost two out of five households who have no members with a disability or long-term illness have an annual income in excess of £20,000 (Scottish Executive, 2004c). The risk of low income is greater for those with a disability or long-term illness who are in single adult or single pensioner households.

The Scottish Household Survey 2001–02 also identified that households with disabled or long-term ill members are less likely to have a bank or building society account. Households with non-disabled members are more likely to have savings or investments (57 per cent). In comparison, 43 per cent of disabled households have some form of savings or investments (Scottish Executive, 2004c).

Capability Scotland (2002) conducted a poll of 152 disabled people and found that:

- a third do not have a current account with a cheque book
- two out of five do not have a debit or credit card
- a third have an occupational or private pension
- a quarter have some form of investment savings like an ISA or shares
- over a third do not have home contents insurance
- less than half have a life insurance policy.

The findings concluded that there is a relationship between poverty and access to financial services, and that disability was also excluding people from accessing such services. According to 1 in 4 respondents, their bank or building society does not provide information in a format accessible to them. And 1 in 5 has been refused life insurance.

The findings go on to suggest that 1 in 10 people with a disability has applied for and been refused a personal loan, compared with 1 in 5 people with a medical condition or illness. Results showed that fewer people with a medical condition or illness have life insurance than people with a disability. And 17 per cent of disabled people think they pay more for their insurance policy, compared with nearly 30 per cent of people with a medical condition or illness.

There are additional consequences for those in the poorest households:

> People who experience an unexpected deterioration in their health, or who have an accident have larger falls in household income than those whose condition develops gradually. For disabled people the chance of gaining employment falls and earnings rise less quickly than for non-disabled counterparts. (Burchardt, 2003)

Individuals in low income households in the UK are more likely to report poor health and to report having a child with a health problem. Individuals on low incomes have been found to be almost three times more likely to develop a mental illness, and levels of reported depression are much higher in the lowest income quintile (Social Exclusion Unit, 2004).

Table 9.2 shows that while workless households run the highest risks of living in poverty (65 per cent), the risk of poverty increases for households with one or more disabled adults (30 per cent) and is less than half (12 per cent) where there are no disabled adults (Riddell et. al, 2005).

Table 9.2: Risk of poverty by disability and employment status

Household type	Percentage in poverty
Household with one or more disabled adult	30
Household with no disabled adult	16
Households with one or more workers	12
Workless households	65

Source: Households Below Average Income 1994–95–2001–02 (Department for Work and Pensions, 2003)

Table 9.3 shows the quintile distribution of household income for working age adults by disability, and shows that families with one or more disabled adults are likely to be poorer than families with no disabled adults (Riddell et. al, 2005).

One study found that families with a severely disabled and/or seriously ill child have low average income compared with families without a severely disabled and/or seriously ill child At the same time these families have significant additional expenditure related to the needs of the disabled/seriously ill child (Woolley, 2004). Many families could not afford to meet these additional costs, and use various forms of credit so that they can bridge the income–expenditure gap. A further report identified that families with disabled children are more likely to be in debt than families without disabled children, and this group has mortgage and rent arrears much higher than in the general population (Harrison and Woolley, 2004). Credit card usage is far higher than usage among the general population, and families with disabled children spend much more than other families servicing their debts.

Table 9.3: Quintile distribution of household income (after housing costs) for working age adults by disability, Great Britain 2001–02 (percentages)

Family	Bottom quintile	Second quintile	Third quintile	Fourth quintile	Top quintile
One or more disabled adults	28	21	19	17	15
No disabled adults	15	14	19	24	28

Source: Households Below Average Income, 1994–95–2001–02 (Department for Work and Pensions, 2003)

One prediction for the future suggests that:

> those most at risk of enduring increased poverty include people with physical or mental disabilities, or chronic health problems, together with their carers, with the risk of being on a low income higher for people with a disability, while their actual living standards may be lower because of their additional living costs. (Social Exclusion Unit, 2004)

9.2 Summary

Disability is both a cause and consequence of poverty, each reinforcing the other, and contributing to increased vulnerability and exclusion. Findings indicate that those with the lowest household income are at the most risk of becoming disabled and vice versa. On the other hand, disabled people are most at risk of enduring poverty, and are also unlikely to be unable to accrue assets during their lifetime. Families with disabled children in particular face the burden of having less money coming in and relatively higher costs in money going out. In policy terms there is a need to address both the causes and consequences of low income and poverty to help those most at risk of lifetime low income.

10 Future demographics

In previous chapters we explored current experiences of disabled people in Scotland. We now move on to offer some commentary on trends and factors that may impact on future demographic projections of the number of disabled people in Scotland.

10.1 Projected population changes in Scotland

Any discussion of the profile of Scotland's disabled people must begin with a broad examination of Scotland's overall demographic profile. Projected demographic trends from the General Register of Scotland (GROS) suggest that Scotland's population will continue to decline, and faster than any other European Union country, over the next 20 years (see Table 10.1) For example, between 2003 and 2021 the population is expected to reduce by 94,000 people.

Table 10.1: Projected population change in Scotland 2000–2021 (thousands)

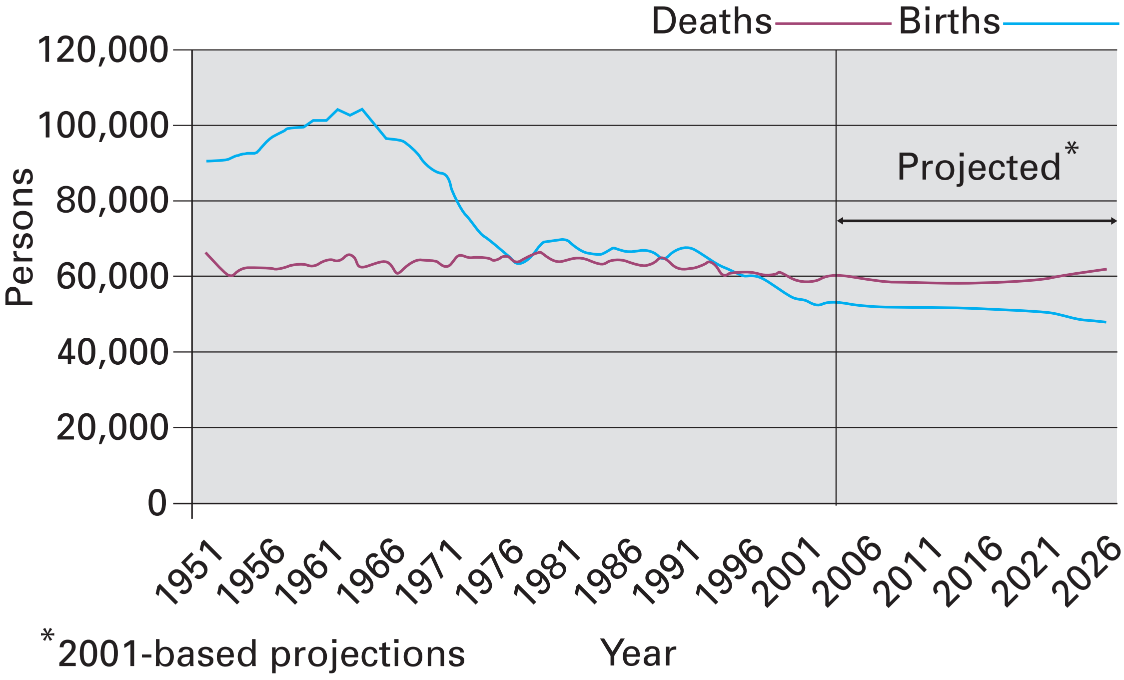
Year	Population
2003 (base)	5,057
2006	5,068
2011	5,034
2016	5,030
2021	4,963

Source: Adapted from General Register Office for Scotland (2004b)

Populations begin to age when fertility declines and adult mortality rates improve, as is the case in Scotland and most of the developed countries around the world. In Scotland, the number of babies born each year has fallen substantially over the last 40 years, to around 52,000 in 2003. The total fertility rate is substantially below replacement levels and, while this is similar to the EU average, it is lower than neighbouring countries in the UK and than every region in England (ESRC, 2005). It is expected to continue to decline slowly in the next 40 years.

Data from the General Register Office for Scotland (2003b) show that 58,000 deaths were registered in Scotland in 2002. This was the lowest total recorded since civil registration began in 1855: it represents a 12 per cent reduction since 1951 and is 5 per cent lower than in 1991. The General Register Office for Scotland found that the majority of deaths occurred at older ages: more than half were of people aged 75 and over, and around a quarter were of people aged between 60 and 75. Future projections by the General Register Office for Scotland indicate that the number of deaths will almost certainly increase over the next 40 years as the large number of people born after the Second World War (baby boomers) and during the 1960s grow older (Figure 10.1).

Figure 10.1: Births and deaths, actual and projected, Scotland, 1951–2026

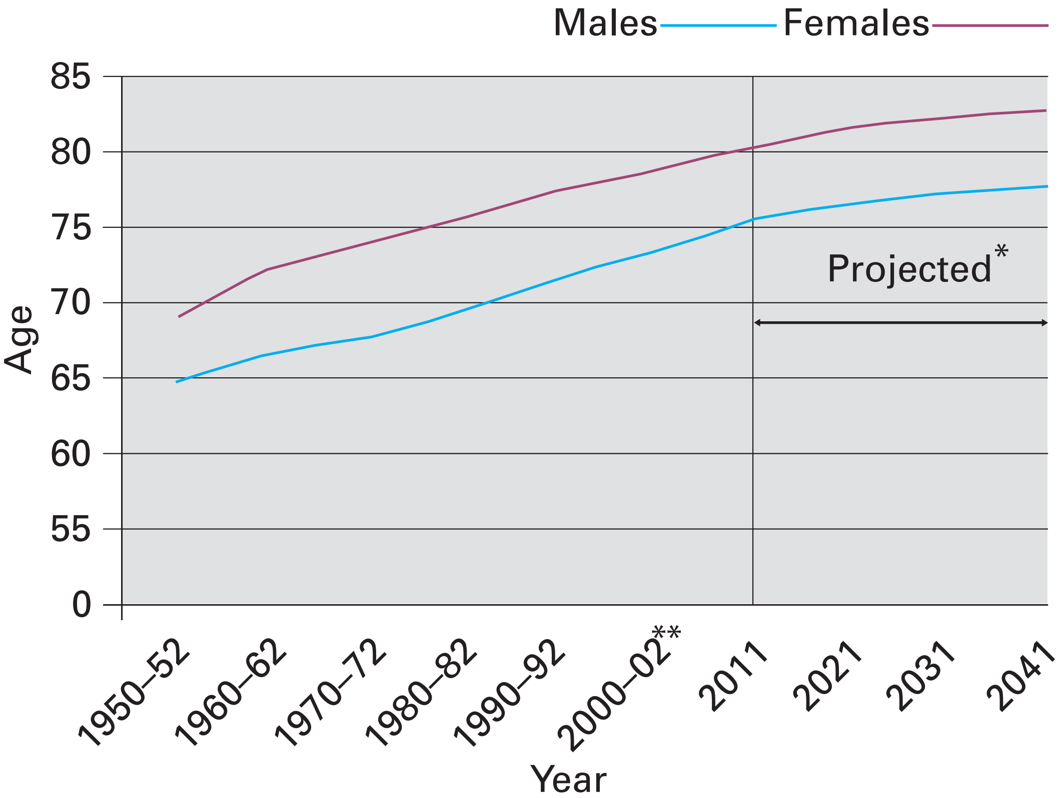


*2001-based projections

Source: General Register Office for Scotland (2003b)

Considerable improvements in life expectancy at birth have been recorded, as shown in Figure 10.2. Boys born in 1951 could, at that time, expect to live to about 64 years, compared with 73 years for those born in 2002. Similarly, girls have experienced an improvement of 10 years, from 68 years in 1951 to 78 in 2002. In the same figure the General Register Office for Scotland illustrates that improvements in life expectancy at birth are projected to continue, rising to 77 for males and 82 for females by 2041.

Figure 10.2: Expectation of life at birth, Scotland, 1952–2041



*2001-based projections
**Provisional

Source: General Register Office for Scotland (2003b)

However, the General Register Office for Scotland further suggests that despite these improvements, Scottish females have the lowest life expectancy at birth in the EU and males the second lowest. For both sexes, life expectancy is more than four years below the countries with the highest life expectancy, and more than two years below the EU average. There are significant differences at a local area level within Scotland: 14 out of 32 council areas have a higher standard mortality ratio (SMR) than the Scottish average, and eight of these are in west central Scotland.

The Research Unit in Health, Behaviour and Change (University of Edinburgh Medical School, 2003) found that for men, there is more than a ten-year difference in life expectancy between the best and worst areas. Its findings indicate that the single greatest influence on how long a man or woman in Britain can live is how wealthy they are, with richer people living longer than poorer people, but that some places do better for a given level of wealth than others. As disabled people tend to be poorer than others in society they would therefore be more at risk of lower life expectancy than many non-disabled people. Evidence points towards factors such as the quality of the environment – both social and physical – making some of the difference, but these have not been fully investigated.

General Register for Scotland data also suggest that although mortality rates have been improving in Scotland, the rate of improvement is slower than elsewhere in the rest of the UK. Since 1976, age-standardised mortality rates have improved by 41 per cent in Northern Ireland and 35 per cent in both England and Wales, compared with 32 per cent in Scotland. Moreover, the rate of improvement is slow by EU standards. Only Portugal of the 15 EU states has recorded a poorer record in recent years.

Mortality rates are forecast to fall, initially at varying rates but tending towards a reduction of one per cent per year at all ages by 2027. In line with the long-term trends, the

General Register Office has assumed that the mortality rates for Scotland will continue to be higher at most ages than those for England and Wales.

Table 10.2: Projected population of Scotland (2003 based) by age group (thousands)

Age group	2003	2006	2011	2016	2021	Net +/–
All ages	5,057	5,068	5,034	5,000	4,963	–94
Under 16	943	913	844	805	787	–156
Working age						
16–29	872	893	901	965	808	–64
30–44	1,150	1,097	981	904	905	–245
45–59/64	1,134	1,185	1,268	1,274	1,381	+247
Pensionable age						
60/65–74	591	600	627	601	573	–18
75+	367	382	413	451	509	+142

Note: Pensionable age is 65 for men and 60 for women until 2010. Between 2010 and 2020 pensionable age for women increases to 65.

Source: Adapted from General Register for Scotland Projected Population of Scotland (2003-based)[6]

We also know that Scotland is predicted to shift towards an older age distribution, at a faster rate than in the UK as a whole. Data provided in Table 10.2 predict a fall in the number of children under 16 and those of working age 30–44, while the number of people of working age between 45 and 59/60 is set to increase. The number of people of pensionable age 60/65–74 shows a marginal reduction, with a larger increase for those over aged 75. This suggests that the ageing process will be slower at the margins.

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[6] www.gro-scotland.gov.uk/statistics/library/popproj/03population-projections.html

10.2 Factors to consider

In trying to make forecasts about the number of disabled people in Scotland over the next 20 years, alongside births, life expectancy and mortality there are other factors that could potentially impact on projections to either increase or reduce overall numbers.

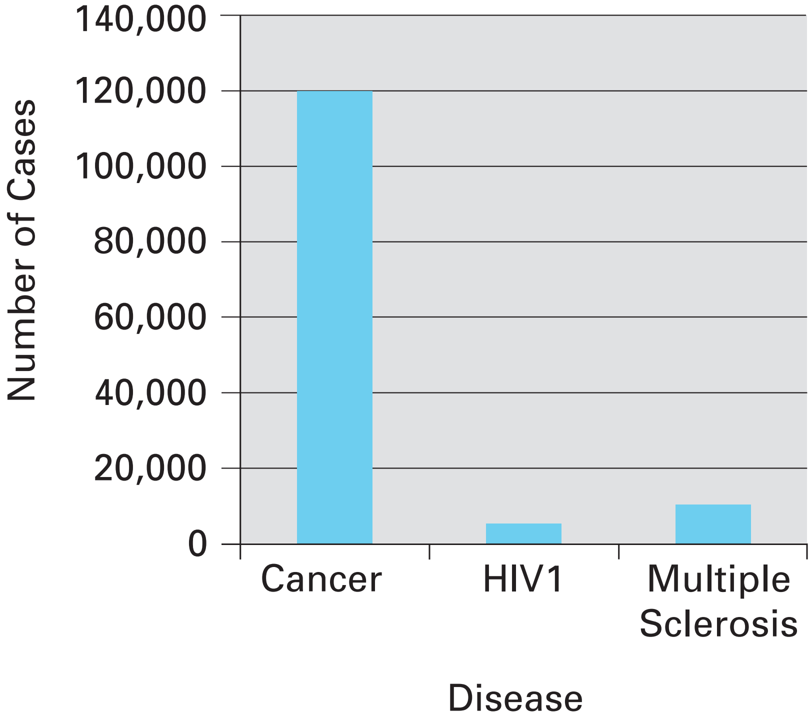
For example, changes in the definition of people covered by the Disability Discrimination Act 2005 to include those with HIV, cancer and multiple sclerosis immediately increases the number of disabled people by 136,000. As illustrated in Figure 10.3, this is broken down as follows:

- the total number of people in Scotland living with cancer at October 2004 was 47,900 men and 72,100 women, a total of 120,000 (Scottish Health Statistics, 2004)
- the total number of people in Scotland infected with HIV1 is 5,500 (NHS Scotland, 2005)
- the estimated total number of people in Scotland with multiple sclerosis is 10,400 (Scottish Parliament, 2004).

Currently, older adults are significantly more likely to have a disability than those in younger age groups, and in addition older people are more likely to suffer from multiple disabilities.

While it is true that each of us will age in different ways depending on a complex interaction of genetic, physical, lifestyle, social and environmental factors, it is feasible to suggest that as the population ages the number of older people with a disability will also increase. For example, by extrapolating from existing incidences of disability (one in two older adults aged over 60 experience some form of disability) on the basis of age alone, it can be estimated that by 2021 about 537,000 people at any one time will have some form of impairment that impacts on their lives.

Figure 10.3: Estimated cases of cancer, HIV1 and multiple sclerosis in Scotland



Source: NHS Scotland (2005), Scottish Health Statistics (2004), SPICe (Scottish Parliament, 2004)

Ageing is inevitable, but healthy ageing is something we should strive for to enable people to extend their contribution to society. The World Health Organisation has delivered a timely reminder that living longer is ‘both an achievement and a perpetual challenge’. It talks about ‘healthy ageing’ rather than programmes for the elderly, and argues that:

> investing in the promotion of health throughout the life span is the only way to ensure that more people will reach old age in good health and capable of contributing to society intellectually, spiritually and physically. (World Health Organisation, 1998)

We are unlikely to achieve anything like the World Health Organisation’s vision of healthy ageing until we confront some of the assumptions we cling to about getting older. We must understand healthy ageing as a process stretching across every stage of our lives – not an event that takes place in the last 10 or 20 years. How we arrive at retirement reflects how we have fared in earlier life and has a critical influence on how our later years will turn out. As things stand, we cannot do much to change our genetic inheritance within our lifetime, but our general health and wellbeing are influenced strongly by our living conditions, lifestyle decisions and our view of the future (McCormick, 2004). If we can improve our working lives, health and standard of living, this will inevitably have an impact on disabilities associated with ageing.

Predictions suggest that while trends in mental health are complicated and difficult to interpret – because of issues such as age-related conditions, patterns of diagnosis, detection, measurement and reporting – there will be a growth in poor mental health and this will be an issue for future healthcare provision (Social Exclusion Unit, 2004).

In the past several years, there has been an increase in diagnosed cases of behavioural difficulties, particularly attention deficit hyperactivity disorder (ADHD), among children. When substantial, diverse and long-term, these conditions are classified as disabilities and covered by the 2001 Special Educational Needs and Disability Act (Scottish Intercollegiate Guidelines Network, 2001). Medically, ADHD was classified in 1994 when attention deficit disorder and hyperkinesis were combined, revised and renamed. In 2001, the Scottish Intercollegiate Guidelines Network (SIGN), (established by the Scottish Medical Royal Colleges) announced recommendations for the diagnosis of ADHD, and suggested that while most estimates of instances of ADHD are between 5 per cent and 10 per cent of school-aged children, the figure could be anywhere between 1.7 per cent and 17.8 per cent, depending on the criteria used.

Scientific and technological developments

Although many advances in science and technology pose challenges to society and its citizens they should be considered in the context of this study. In order to reach a better understanding of the implications we need to engage the public in dialogue to explore the different views that are fundamental to making these kinds of decisions. As a society we are not yet at the stage where we have found progressive ways through new dilemmas, as well as longstanding ethical challenges, to a position where what is possible in terms of scientific and technical advances and what is acceptable to society as a whole can be managed.

- Stem Cell Research: Scientists reported in November 1998 that they had successfully isolated stem cells, which have the potential to develop into many different cells and can reproduce themselves. Cell-based therapies could potentially be applied to replace damaged organs and tissues. This means that in the not-too-distant future the technology could be used to treat conditions such as Alzheimer's disease, spinal cord injuries, diabetes and Parkinson's disease, to name but few. Already scientists have successfully experimented with stem cell research to develop insulin-secreting cells (for potential treatment of diabetes) and to increase the mobility of paralysed animals.
- Prenatal Screening: Prenatal screening is already available in the UK and is used to detect conditions in the unborn child such as Down's syndrome and cystic fibrosis. Parents can then decide whether or not to terminate the pregnancy based on the information gained from the screening. Embryos created for in vitro fertilisation (IVF) treatments can also be screened for genetic conditions. The mapping of the human genome may allow doctors to identify other genetic conditions in the unborn child. In theory almost any genetic condition could be detected with the application of prenatal screening.

10.3 Future predictions

Population estimates are difficult. Both the General Register Office for Scotland and the Government Actuary's Department have changed their projections annually since 1999, based on new or revised statistical data and evidence.

For Table 10.3 we have initially used data from the 1991 Census showing a breakdown by age and gender of people who have a limiting long-term illness. The next column shows the percentage who have a limiting long-term illness compared with the population as a whole. Assuming all things to be equal, we then applied the 1991 percentages of disabled people to project 2001 figures. These we compared with the actual data from the 2001 Census.

The results showed that by 2001 the actual number of people with a limiting long-term illness had increased for all age groups and for both males and females. The most striking differences were in the age groups 55–64, 65–74 and 75+. We are, however, unable to determine whether this is because more people are self-reporting as having a limiting long-term illness or whether there has been an increase in illness and/or disability. There was also a rise among children between the ages of 5 and 15 who, in 2001, were more than twice as likely to be reported as having a long-term illness as in 1991. In addition, more than 80 per cent more people between 15 and 44 reported a limiting long-term illness in 2001 than in 1999.

For Table 10.4 we took the 2001 Census data, along with the 2001-based population projections to 2021, and estimated how many people there would be with a disability or limiting long-term illness if, all things being equal, the percentages by age and gender were stable between 2001 and 2021.

Our assumptions were that:

- overall levels of disability or limiting long-term illness were to remain at 2001 levels

- the number of people with a disability or limiting long-term illness increases with age, (in 2001 it was 12.7 per cent for those aged 35–44, rising to 56.6 per cent for those aged over 75), and
- the number of older people in Scotland is predicted to rise, therefore
- the number of people with a disability or limiting long-term illness would also increase.

We did not factor in any of the variables identified above under 'Factors to consider'.

The results show that:

- from a baseline of 5,063,000 people in Scotland in 2001, 978,000 (19 per cent) were defined as having a disability or limiting long-term illness
- by 2006, the population is expected to be 5,023,000, of whom 1,004,000 (20 per cent) are expected to have a disability or limiting long-term illness
- by 2011, the population is expected to be 4,983,000, of whom 1,029,000 (21 per cent) are expected to have a disability or limiting long-term illness
- by 2016, the population is expected to be 4,943,000, of whom 1,060,000 (21 per cent) are expected to have a disability or limiting long-term illness
- by 2021, the population of Scotland is estimated to be 4,894,000 (a reduction of 169,000 from 2001), of whom 1,087,000 (22 per cent) (an increase of 109,000 from 2001) are estimated to have a disability or limiting long-term illness. This can mainly be attributed to an increase in the number of older people.

More specifically between 2001 and 2021:

- the number of children between birth and four is predicted to reduce from 276,000 in 2001 to 248,000 in

2021. This would mean the number of young children identified as having a disability or limiting long-term illness would reduce from 8,500 to 7,600

- the number of children between five and nine is predicted to reduce from 306,000 in 2001 to 251,000 by 2021. This would mean the number of children with a disability or limiting long-term illness would reduce from 15,800 to 13,000
- the number of young people between 10 and 14 is predicted to reduce from 323,000 in 2001 to 251,000 by 2021. This would mean the number of young people with a disability or limiting long-term illness would reduce from 17,400 to 13,500
- there will be a slight increase by 2006 of those aged 15–24, to 654,000, and then the numbers are expected to fall between 2007 and 2021 to 551,000. This would mean the number of people in this age group with a disability or limiting long-term illness would reduce from 36,700 to 31,900
- the number of people aged 25–34 is estimated to decrease between 2001 and 2021 from 696,000 to 621,000. This would mean the number of people with a disability or limiting long-term illness would reduce from 63,800 to 57,000
- the number of people between 35–44 is estimated to decrease from 782,000 in 2001 to 590,000 by 2021. This would mean the number of people with a disability or limiting long-term illness would reduce from 99,500 to 75,200
- increases in those aged 45–54 are expected until 2016, when the numbers are estimated to be 752,000, then the number will reduce to 658,000 by 2021. This would mean the number of people with a disability or limiting long-term illness would reduce from 140,500 to 134,400

- the number of people aged 55–64 is expected to increase from 552,000 to 716,000. This would mean the number of people with a disability or limiting long-term illness would increase from 191,100 to 248,000; an increase of over 50,000
- those aged 65–74 are expected to increase from 446,000 to 558,000. This would mean the number of people with a disability or long-term illness would increase from 201,300 to 252,100; again, an increase of over 50,000
- those aged over 75 are predicted to rise from 360,000 in 2001 to 450,000 by 2021. This would mean the number of people with a disability or limiting long-term illness would rise from 204,000 to 254,700; again, an increase of over 50,000
- women aged over 25 are expected to outnumber men in all age groups.

10.4 Summary

Looking forward, Scotland can expect to see fewer people overall, especially in the younger age groups, and more older people aged 55 and over. The main cause of both population decline and ageing is low fertility.

If the population is ageing and there are fewer people of working age, this could be an opportunity for disabled people who may have traditionally not had access to job opportunities to become part of the workforce. Disabled people have untapped employment potential.

Mortality rates have declined steadily, but early mortality remains high by European standards. Scotland needs to close the gap between improving life expectancy and healthy life expectancy. While life expectancy has risen by almost ten years on average in the past 50 years, healthy life expectancy has risen more slowly, as measured by years free of limiting illness or health conditions. This has advanced by about four years over the same period. Because the likelihood of having a disability increases with age, and there will be more older people, this means that the proportion of people in Scotland with a disability seems likely to increase in future.

Data are only as good as the assumptions on which they are based, and cannot take into account what is as yet unknown, particularly when it comes to projecting into the future. There will be differences of opinion about size of the overall population, and about the number of disabled people living in Scotland in the future. However, the lack of precise data should not limit our ability to make serious decisions about the future delivery of public policy and services to create a more equal and inclusive society. Key principles for the future should build on offering personalisation, choice and equality as both good and necessary within public services.

Table 10.3: Percentage of population reporting long-term illness in 1991 and 2001 (thousands)

	1991			2001			
Age range	Total based on Census data	LLTI	1991 actual %	Total based on Census data	2001 LLTI based on 1991	2001 actual LLTI	2001 actual %
0–4	317	6.1	1.93	276	5.3	8.5	3.1
Males	162	3.5	2.2	142	3.1	5.0	3.5
Females	155	2.6	1.7	134	2.3	3.5	2.6
5–15	693	17.5	2.5	629	15.8	33.2	5.3
Males	355	10.2	2.9	322	9.2	19.9	6.2
Females	338	7.3	2.2	306	6.6	13.3	4.3
15–44	2,169	110.7	5.1	2111	107.7	199.9	9.5
Males	1,071	54.9	5.1	1036	53.1	96.8	9.3
Females	1,098	55.8	5.1	1076	54.7	103.1	9.6
45–54	578	82.7	14.3	689	98.5	140.5	20.4
Males	283	40.5	14.3	341	48.7	67.3	19.7
Females	295	42.2	14.3	348	49.8	73.2	21.0
55–64	537	140.0	26.1	552	143.9	191.1	34.6
Males	254	74.3	29.2	267	78.1	95.3	35.7
Females	283	65.7	23.2	285	66.2	95.7	33.6
65–74	440	140.1	31.8	446	141.9	201.3	45.1
Males	191	64.7	33.8	200	67.6	93.2	46.6
Females	249	75.4	30.3	246	74.5	108.1	43.9
75+	327	137.8	42.2	360	151.8	203.9	56.6
Males	107	43.8	41.1	126	51.7	70.7	56.1
Females	220	94.0	42.7	234	99.9	133.2	56.9

Table 10.4: Projected population with a disability or limiting long-term illness (LLTI) by age based on 2001 percentages (thousands)

	2001			2006	
Age range	Total based on Census data	Disability and LLTI	%	Projected total population	Projected total with LLTI
0–4	276	8	3.1	256	8
Males	142	5	3.5	131	5
Females	134	3	2.6	125	3
5–9	306	16	5.2	276	14
Males	156	10	6.2	142	9
Females	149	6	4.1	134	5
10–14	323	17	5.4	305	16
Males	166	10	6.1	156	10
Females	157	7	4.6	149	7
15–24	633	37	5.8	654	38
Males	319	19	6.0	331	20
Females	314	18	5.6	324	18
25–34	696	64	9.2	609	56
Males	337	31	9.2	296	27
Females	359	33	9.1	313	29
35–44	782	99	12.7	776	98
Males	380	47	12.3	372	46
Females	403	53	13.1	403	53
45–54	689	141	20.4	705	144
Males	341	67	19.7	344	68
Females	348	73	21.0	360	76
55–64	552	191	34.6	616	213
Males	267	95	35.7	300	107
Females	285	96	33.6	316	106
65–74	446	201	45.1	451	204
Males	200	93	46.6	207	96
Females	246	108	43.9	245	108
75+	360	204	56.6	375	212
Males	126	71	56.1	138	77
Females	234	133	56.9	237	135
Total	5,063	978		5,023	1,004
Total %			19		20

Table 10.4 (continued)

Age range	2011 Projected total population	2011 Projected total with LLTI	2016 Projected total population	2016 Projected total with LLTI	2021 Projected total population	2021 Projected total with LLTI
0–4	252	8	251	8	248	8
Males	129	5	129	5	127	4
Females	123	3	122	3	121	3
5–9	256	13	252	13	251	13
Males	131	8	129	8	129	8
Females	125	5	123	5	122	5
10–14	276	15	256	14	251	13
Males	142	9	131	8	129	8
Females	134	6	125	6	122	6
15–24	647	37	600	35	551	32
Males	327	20	304	18	279	17
Females	319	18	297	17	271	15
25–34	607	56	629	58	621	57
Males	297	27	309	28	306	28
Females	310	28	320	29	316	29
35–44	679	86	592	75	590	75
Males	323	40	282	35	284	35
Females	355	46	310	41	308	40
45–54	758	155	752	154	658	134
Males	363	72	357	70	309	61
Females	395	83	395	83	349	73
55–64	646	224	664	230	716	248
Males	314	112	318	114	337	120
Females	332	111	346	116	380	128
65–74	469	212	529	239	558	252
Males	219	102	248	116	261	122
Females	251	110	280	123	297	130
75+	393	224	418	236	450	255
Males	153	86	167	94	185	104
Females	242	138	250	142	265	151
Total	4,983	1,029	4,943	1,060	4,894	1,087
Total %		21		21		22

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Acknowledgements

The authors of this report would like to thank the Disability Rights Commission (Scotland) for their kind support.

Their support does not imply agreement with our findings.

Responsibility for the content of the report, including any errors, rests with the Scottish Council Foundation. The information contained in this report is correct as published and does not take into account errors made by individual authors.

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