

INDEPENDENT LIVING IN SCOTLAND

A Policy Scoping Study

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2007

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EXECUTIVE SUMMARY

This report presents the findings of a policy scoping study on independent living in Scotland, commissioned by the Disability Rights Commission (DRC). The study examines current policy issues relevant to independent living and highlights opportunities and challenges for the promotion of independent living, providing a starting point for the development of a wider strategy.

Background and the need for the study

Recent years have seen a growing recognition of the need for independent living for disabled people, defined by the DRC as:

“all disabled people having the same choice, control and freedom as any citizen - at home, at work and as members of the community”. (DRC, 2002)

Independent living is based upon the adoption of the social model of disability and involves providing appropriate support to enable disabled people to participate fully across the spectrum of economic, social, political and cultural life, giving them control of all aspects of their lives. The need for independent living is based upon evidence that disabled people do not currently have access to the opportunities, services and participation which non-disabled people take for granted. There are a range of benefits for individuals from independent living, and economic benefits for society. Enabling independent living is also “a process of empowering people to exercise their human rights”.

The report identifies 5 broad areas in which appropriate provision is required in order to achieve independent living. These are:

- The political, social and service structure.
- The environment.
- Personal support and services.
- Opportunities for economic and social participation.
- Funding and resources.

The report examines key relevant developments in each area, as well as the barriers to independent living and equality which remain, despite the expressed intention of some of the changes.

The political, social and service structure

The **decision making structure** for equalities work in Scotland has developed with devolution, with some positive developments in equalities work in recent years. The Scottish Parliament and Scottish Executive have a role in promoting equality, and the DRC has a statutory remit to eliminate discrimination and promote equality for disabled people. National and local voluntary organisations, local authorities, NHS bodies and others also have a role. There is, however, a lack of explicit structure for considering independent living, and no Independent Living Task Force in Scotland. There can also be a lack of joined-up thinking and communication, as well as variation in commitment to independent living and a lack of leadership and strategic approach. There are also concerns about the input from Scotland to reserved issues, and the impact of the CEHR on equalities work in the future.

There have been a number of overarching developments in **policy and legislation** relevant to independent living, including: the Disability Discrimination Acts 1995 and 2005; the Equality Act (2006); the report “Improving the Life Chances of Disabled People” (PMSU, 2005); the establishment of a UK Expert Panel on Independent Living and national Office for Disability Issues; the DRC’s Disability Agenda and other developments. Although there has been an increasing acceptance of a rights-based approach to disability equality, however, some policy and legislation does not reflect a commitment to independent living. It may use the medical model of disability and inappropriate terms, or may have the practical effect of undermining independent living. Impact assessment is not yet carried out consistently, and the potential economic benefits of independent living may not be taken into account. Disabled people also still have few legislative rights to services, and it can be difficult to enforce existing entitlements.

There has been a growing commitment to **inclusion and empowerment** of disabled people, with examples of consultation with, or involvement of disabled people in policy and practice, and removing barriers to engagement. A national forum (Equality 2025: the United Kingdom Advisory Network on Disability Equality) is being established, and the requirements of the DDA (2005) are likely to increase the involvement of disabled people in shaping policy and practice in the future. It remains the case, however, that

the views of disabled people are often not sought on issues which affect them and there are not always clear mechanisms for involvement. There can be a lack of capacity in organisations led by disabled people, and a lack of resources to enable individual disabled people to take part in consultation, or a lack of willingness to involve them. Where involvement does take place, there can be problems with the ways in which it is undertaken.

Disability-led organisations have a strong role in providing **information, advice and advocacy** and these services are popular with users and can be cost-effective. The Scottish Executive has accepted a recommendation relating to supporting independent advocacy services for disabled people nationwide, and steps have also been taken to improve the manner in which information is provided to disabled people. Provision varies across Scotland, however, with a lack of an overall network of user-led organisations to support independent living, gaps in some forms of support, and many organisations facing funding constraints. Disabled people are often unaware of support, or cannot access it, and people who have communication support needs can experience inappropriate responses.

In terms of **attitudes and behaviour** towards disabled people, there is some evidence that these are generally improving. Some campaigning work has been carried out, and the provision of disability equality training has increased. There is strong support in Scotland for action to tackle hate crimes, and there have been some developments to the promotion of equality through the media. There is also strong evidence, however, of problems with some attitudes and behaviour towards disabled people, and many disabled people experience prejudice and abuse from the community, and inappropriate responses from service providers, employers and colleagues. Disabled people themselves can hold negative attitudes about their abilities, and the media can sustain such attitudes. There are also gaps in disability equality training.

There have also been a number of cross-cutting developments to **service provision**, with a commitment to public service reform and an increased emphasis on choice and control by users in the design, delivery and evaluation of services. A number of recent national reports and local strategies also have cross-cutting implications for service provision. There are, however, many barriers in service provision, and access to services is generally

poorer for disabled people than non-disabled people. There can be fragmentation and variation in practice, procedures and goals, and problems with physical access to services, availability, affordability and the nature of provision. Information can be patchy, inappropriate or inaccessible and services are often designed and provided to suit providers and driven by cost, rather than need. There is little measurement of performance against factors which would indicate the promotion of independent living.

The environment

There have also been some improvements to the **built environment**, with increasing recognition of issues for disabled people and the DDA having raised the profile of the need to improve access. There is good practice guidance available, and access panels provide advice. The Scottish Executive has stressed the need for a more inclusive built environment, and changes to planning legislation and building regulations should lead to further improvements in the future. Many premises, however, remain inaccessible, and many buildings pre-date the legislation. Some issues are not subject to building regulations and standards, and improvements may not address problems fully. There has been a lack of funding for access improvements, and there is often limited involvement of disabled people in considering access, with variations in access panels between different areas. There can be a lack of understanding of issues affecting disabled people, a lack of joined-up thinking and a tendency to meet only minimum requirements.

There have also been some developments to the accessibility of **transport** and the DDA brought detailed requirements for access. Issues for disabled people are specified in the Transport Strategy for Scotland, and Scottish Executive guidance makes it clear that regional and local transport strategies should address access issues. Disabled people, however, do not currently have equal access to transport services, with many vehicles inaccessible, and the pace of improvement slow. Other barriers include: the costs of transport; lack of accessible journey information; timing of services and the need to book in advance; lack of confidence that needs will be met; a high level of abuse of reserved parking bays; and negative attitudes from transport providers and members of the public. The fact that disabled people travel less often also has implications for transport providers in terms of lost revenue.

There has also been a range of key **housing** legislation in recent years which has identified some of the needs of disabled people and has made some changes to address these. The DDA brought changes to housing rights and duties. Assessments for local housing strategies require to cover the need for, and availability of, housing for people with “special needs”. The “Partnership Agreement” expressed a commitment to ensuring that more homes are barrier-free, and the concept of enabling people to live in their own homes has been emphasised in other documents. There is, however, a shortfall in the availability of housing suitable for disabled people and there can be problems with adaptations and other issues. There is a lack of statistical information about housing needs and suitable provision. Issues facing disabled people are not always reflected in strategic documents, and the objectives of different housing policies can conflict.

Personal support and services

In terms of **health and community care** services, there have been a number of legislative developments relevant to independent living, and developments to the accessibility of health and social care facilities, communication and information provision. Legislation has promoted joint working between health and local authority services and there has been a shift in health and social care policy towards supporting people to remain in their own homes, with a number of relevant strategic and policy commitments. As with other policy areas, however, disabled people face barriers to health and community care services, including provision which does not always meet their needs, and limited knowledge of disability issues among some staff. There can be confusion between social care, personal care and health care, as well as concerns about how some care is delivered, and a lack of information and support. Financial pressures can also constrain services’ implementation of independent living.

A further major change has been the development of **Direct Payments**, with disabled people now having the option of purchasing support on an individual basis. There are also two Independent Living Funds which can be used to buy personal care in the community. There are many accounts of the benefits of Direct Payments for disabled people, with evidence that they can represent a significant cost saving to services and the Exchequer.

Although the number of Direct Payments in Scotland is rising, however, there remain many disabled people who do not use them, with variation between areas. Barriers to their use include: a lack of infrastructure for Direct Payments; capacity issues for user-led support organisations; a lack of “championing” of Direct Payments; reluctance in some local authorities to support them; lack of flexibility; resource problems; concerns about users’ contributions to care; and problems for some disabled people as purchasers of care.

Opportunities for economic and social participation

There have also been developments in **employment** opportunities for disabled people, and the DDA (1995) has implications for employment rights. The Green Paper “A New Deal for Welfare: Empowering People to Work” aims to ensure that people who are able to work have the opportunity to do so, and a range of schemes provide support with employment issues. Disabled people, however, have a poorer employment position than non-disabled people, and are more likely to be dependent on benefits. There can be a tension between policies which encourage people to enter employment and others which make it difficult to do so, and many support services are not organised in a way that enables users to participate in work, education or training. A number of barriers are identified with employment-focused support, government schemes, work experience and self-employment, and there is a lack of support, information and incentives to recruit and retain disabled people.

There have also been changes in **education and training**, with the Scottish Executive committed to promoting participation in education and learning. A range of relevant educational legislation, alongside the DDA, has led to developments to address issues for disabled people. There has been an increasing move to educate disabled children and young people in mainstream schools and a recognition of the importance of transition points. It remains the case, however, that disabled people often have poorer experiences and outcomes in education and training than non-disabled people. There are barriers such as: physical access; a lack of support at times which can enable attendance; limited access by disabled people to information about choices; provision of support and equipment which is linked to a particular setting; delays and difficulties with support at transition times; negative

attitudes; and a lack of recognition of independent living in education and training policies and strategies.

There have also been developments to **leisure, social and public life**, and the leisure and social activities available to disabled people have expanded. Policies and strategies have been developed, and work has been done to facilitate access to leisure and information. Disabled people are still, however, often excluded from activities, and there is a general lack of disabled people in positions of authority and public life. Barriers in facilities can be compounded by barriers in the environment (such as transport), activities are not always available at appropriate times, and gaps in support can constrain participation. Many sport and cultural activities also face funding problems and, as in other policy areas, strategic documents do not always make reference to disabled people. Attitudes can be a further barrier to participation, and there can be confusion about issues such as the impact of volunteering on benefits.

In terms of **income**, there have been recent major developments to the welfare system. The Scottish Executive has an expressed commitment to social justice / social inclusion and there have been a range of initiatives recognising that disabled people face additional costs. Disabled people, however, continue to face income inequality and are more likely to live in poverty than non-disabled people. This is linked to barriers in employment, education and training and has an impact on access to housing, transport etc. The benefits system can also create barriers to income, and it has been suggested that the level of provision to disabled people is insufficient to reflect their additional costs.

Funding and resources

There is a complex range of **funding** which is relevant to independent living. Generally, however, it has been suggested that insufficient funding has been made available to support independent living, with an overall lack of recognition of the considerable economic benefits of this. Limitations to funding for equalities work have also been noted, as well as a gap in resources for disabled people's organisations and a suggested lack of specific resources for independent living at a local level. Financial pressures and competing demands on budgets can also lead to a lack of priority for independent living. There have been

reductions in some relevant funding, and some specific funding issues have been identified with Direct Payments. Existing resources are not always used most efficiently, and there can be fragmentation, complex funding arrangements and some duplication of services.

The way forward

In the light of the findings, the report makes many suggestions for objectives and actions which might form the basis of a future strategy for independent living in Scotland.

In relation to the **political, social and service structure**, the suggested objectives are to:

- Create a political and organisational structure in Scotland which recognises and promotes independent living and equality for disabled people.
- Ensure that there is a clear commitment to independent living, and that all legislation, policy and practice which develop in Scotland are consistent with the principles and goals of independent living.
- Promote full involvement and participation in decision-making on an equal basis by disabled people, and ensure that there is appropriate support in place to enable this.
- Ensure that the concepts of equality and independent living for disabled people are widely understood and supported throughout Scottish society.
- Develop service provision and practice which promote, support and sustain independent living for disabled people.

In relation to the **environment**, the suggested objectives are to:

- Develop a built environment in Scotland which is fully accessible to disabled people and enables them to use all public spaces on a safe and equal basis and to access opportunities for economic and social participation.
- Develop a fully integrated, affordable and accessible transport system in Scotland which enables disabled people to have full and equal choice of where and when

they travel and to access opportunities for economic and social participation.

- Provide public and private housing which meets the needs of disabled people and enables them to choose the location and type of their housing.

In relation to **personal support and services** the suggested objectives are to:

- Provide appropriate, comprehensive and enabling personal support to disabled people, which promotes and sustains independent living.
- Enable disabled people to have full control of the nature of their support and the ways in which it is provided, and develop a robust system which locates control of all relevant resources with individual service users.

In relation to developing **opportunities for economic and social participation**, the suggested objectives are to:

- Ensure that recruitment and employment practices in Scotland enable disabled people to have equal access to employment, and that appropriate support is provided to enable them to gain, sustain and retain employment.
- Develop an inclusive education system that enables disabled people to participate fully and equally in all aspects of this, and develop equal access to all forms of training.
- Develop facilities and provision to enable full and equal participation by disabled people in all aspects of leisure, social and public life.
- Provide a benefits system which recognises the additional costs faced by disabled people, and meets their financial requirements, whilst avoiding the creation of additional barriers to participation in other aspects of life.

In relation to **funding and resources**, the suggested objective is to:

- Recognise the economic benefits of independent living and ensure the provision of adequate long term sustainable resources to support all of the developments

which will be required to enable full choice and participation by disabled people in all aspects of their lives.

The report identifies a large number of potential actions, which focus on:

- **Creating appropriate decision making structures**, with suggestions including to: establish an Independent Living Task Force; make links to other key stakeholders and relevant bodies; establish mechanisms for cross-governmental and interdepartmental work on independent living; monitor the CEHR; establish local multi-agency structures and other mechanisms for joint working.
- **Making policy and legislation to meet the needs of disabled people**, with suggestions including to: develop a national independent living strategy for Scotland, with local strategies; ensure support from policy makers and practitioners; identify independent living as a priority; ensure common definitions; identify, implement and enforce relevant legislation and policies; consider the provisions of the Independent Living Bill and whether legislation is required in Scotland; undertake 'proofing' and impact assessment; reflect the commitment to independent living in legislation, policies, strategic documents, guidance, initiatives, service developments and reviews; use the Disability Equality Duty to promote independent living; and examine organisations' implementation of relevant actions.
- **Ensuring that reserved matters reflect the needs of Scotland**, with suggestions including to: raise issues with the UK Government relating to employment and training, income and poverty, transport and the accessibility of services and Direct Payments, and monitor the outcomes of the individual budgets pilots currently operating.
- **Ensuring the inclusion and empowerment of disabled people**, with suggestions including to: involve disabled people in new structures and across policy areas at all levels, from the earliest stage; identify current representation and inclusion of disabled people, address

any gaps or barriers and promote opportunities for increased participation; ensure the further development of representative organisations of disabled people; where necessary, develop new mechanisms for involvement; and develop further information and guidance relating to the involvement of disabled people.

- **Delivering information, advice and advocacy**, with suggestions including to: identify the need for specific information, advice and advocacy services to support independent living; ensure the development of services in all local authority areas; develop forms of provision which address the needs of disabled people and promote good practice; improve access to information, advice and advocacy and develop accessible information on a wide range of issues.
- **Addressing attitudes and behaviour**, with suggestions including to: develop a package of national and local measures to promote positive attitudes; develop work with young people; encourage good practice across organisations; develop and disseminate guidance and information; develop the provision and use of disability equality training; provide training to disabled people; identify other opportunities to address attitudes; identify key research issues; and take action against inappropriate attitudes and behaviour.
- **Developing effective service standards and service outcomes**, with suggestions including to: develop common standards, performance indicators and guidance, a framework of goals, targets and minimum entitlements; develop relevant Best Value and other performance indicators; ensure specific consideration of independent living and disability equality in inspection and performance measurement; develop inspection criteria; collect appropriate monitoring information; and ensure that there are accessible and well-publicised complaints procedures in place.
- **Delivering services to meet the needs of disabled people**, with suggestions including to: continue to develop needs-based planning; develop specific initiatives

to improve information; develop joint working; ensure that services are responsive, integrated and user-centred; develop accessibility; encourage organisations to put in place developments beyond the minimum requirements; develop seamless provision; use procurement processes to support independent living; develop incentives; and identify and address any barriers.

- **Funding and sustaining independent living**, with suggestions including to: identify a common, evidence-based view of the costs and benefits of independent living in Scotland; identify funding issues in existing key strategies and reports; consider the distribution of current resources; develop flexible approaches to funding and commissioning services; address some of the barriers to grant funding, and specific issues relating to resources in particular services; ensure appropriate long term resources to support independent living; and ensure that funding provision supports the use of Direct Payments.

It is recognised that the implementation of these changes will require input from a range of participants and the report concludes that, taken together (and alongside other work to promote disability equality), these changes would enable the choice, control and freedom which are required for independent living in Scotland.

SECTION 1: INTRODUCTION

1.1 Reid Howie Associates was commissioned by the Disability Rights Commission (DRC) in late 2006 to carry out a policy scoping study on independent living in Scotland. This report presents the findings.

THE PURPOSE AND NATURE OF THE STUDY

1.2 The overall aim of the study was identified as being:

“to identify and critically examine the evidence of positive and negative policies which may impact on independent living”.

It was agreed that it should make recommendations on current opportunities and challenges in implementing independent living in Scotland, and help to identify a strategy for independent living policy implementation. The study provides a starting point for this.

1.3 The study was based mainly on an examination of relevant literature, and material from national and local organisations¹. It was anticipated that the next stage would involve discussion by the DRC of the findings of the report with disabled people in Scotland (who will then be involved in taking this work forward).

1.4 It was, however, also considered appropriate to involve a small number of organisations with a key interest in independent living at this stage. Meetings were held with three such organisations, and an opportunity was also provided (via a range of organisations) for individual disabled people to provide information about their own experiences of independent living. The findings from these strands have been included at relevant points within the report. Full details of the methodology are provided at Annex 1.

The focus of the study

1.5 The focus of the scoping study is particularly upon disabled adults. It is recognised, however, that the experiences of children and young people impact upon their future opportunities, and, although there

¹ Although this is rarely attributed to individual organisations, it has been used throughout the report in the provision of examples.

is not a detailed focus on the provision of services and support to them, some of the key issues, particularly in relation to education, are highlighted. It is also acknowledged that some of the findings are relevant to older people.

The report

1.6 The report is in four sections with three annexes:

- The remainder of Section 1 defines independent living and the social model of disability, and outlines the main requirements to enable independent living.
- Section 2 identifies key developments in policy and practice and the overall context in Scotland, highlighting some of the legislation and policy and some positive changes which might impact upon each of the components of independent living.
- Section 3 identifies some of the negative impacts of some aspects of policy and practice upon independent living, identifying some of the barriers to independent living and the key challenges.
- Section 4 makes a range of suggestions for change which might form the basis of a future strategy for independent living in Scotland.
- The three annexes provide a methodology, a bibliography and a list of abbreviations.

INDEPENDENT LIVING

1.7 Recent years have seen the growth of the independent living movement amongst disabled people. Campaigning work has been undertaken to highlight the current lack of equal access to choice and control which disabled people experience, and their lack of access to the opportunities, services and participation which non-disabled people take for granted. Evidence is also emerging to suggest that there are economic benefits for society as a whole from independent living. This has led to an increasing recognition of the need for independent living which is defined by the DRC as:

“all disabled people having the same choice, control and freedom as any citizen - at home, at work and as members of the community”. (DRC, 2002)

1.8 Independent living is not simply that disabled people are able to live in their own homes, although clearly that is one aspect of this. Neither is it just about the means of providing social care, nor is it a community care service in itself. The concept of independent living involves providing appropriate support to enable disabled people to participate fully across the spectrum of economic, social, political and cultural life, giving them control of all aspects of their lives. As the DRC (2007a) states:

“the emphasis of independent living is on disabled people making decisions about their lives ... the goal of independent living is that disabled people have the same opportunities as non-disabled people to participate in community life”.

1.9 In essence, it is about empowering all disabled people to have choice and control in all aspects of their lives, with the appropriate mechanisms and services in place to enable this.

1.10 As a result, it has implications for the ways in which needs are identified and support and services provided across a range of policy areas. These include: planning and the environment; transport; housing; health; social care; employment; education and training; leisure; and benefits (and potentially all aspects of social and public policy). The DRC (2007a) notes that:

“The concept of independent living embraces all aspects of life ... the existence or absence of barriers to engaging in these areas of life will determine whether disabled people are able to be active citizens.”

1.11 Within this definition, it is recognised that independent living:

“... does not necessarily mean disabled people ‘doing everything themselves’ but it does mean that any practical assistance people need should be based on their own choices and aspirations.” (DRC, 2002)

1.12 Such an approach has implications for: policy, legislation and strategy; decision making; and service planning, delivery and review. It involves a particular approach to the way in which disability is viewed, with the adoption of a social model of disability. There is a the need for individualised approaches to provision which recognise the diverse experiences amongst disabled people. It is also recognised that:

“any meaningful concept of equality must extend beyond equal treatment, and must not only seek to eliminate the inherent barriers to equal opportunities but also, in some cases, extend to providing additional resources to address the lack of opportunity.” (DRC, 2007a)

The social model of disability

1.13 The social model of disability is a theoretical approach which identifies disability as being caused by the lack of an appropriate response by society to an individual’s impairment (rather than being caused by the impairment per se). An individual is disabled by external factors (such as a lack of accessibility or inappropriate social attitudes) which prevent them from participating fully in aspects of economic, social, political and cultural life.

1.14 This contrasts to a medical model of disability, which sees the individual as being disabled by their impairment, and identifies the “problems” as located with the individual. The social model’s definition of disability distinguishes it clearly from impairment or ill-health, and focuses instead on the disadvantage experienced as a result of the barriers which impact upon people with impairments and / or who are experiencing ill-health. Within this definition, the action seen to be required is to remove the barriers within society which prevent participation by disabled people, and inhibit independent living.

The need for independent living

1.15 There is a growing recognition of the need for independent living for a range of reasons, and there is evidence of its benefits. A recent report (SQW, 2007) summarises that there is:

“... extensive qualitative information on independent living benefits and the improvements delivered in terms of physical and emotional well-being. The literature documented particular enhancements in health status, satisfaction, participation in society, motivation, self esteem and greater degrees of choice to mention but a few.”

These benefits were supported in responses from disabled people to this research.

1.16 The need for independent living is also clear when the current position of disabled people is examined (discussed in more detail in Section 3). Evidence suggests that:

- The built environment is currently inaccessible to many disabled people.
- Disabled people do not have equal access to transport services or to housing.
- There are barriers to some aspects of health and community care services.
- There are constraints to the participation of disabled people in education, employment, leisure, social and public life.
- Many disabled people live in poverty.
- There are many gaps in legislation, policy, services and support to disabled people.
- Disabled people experience inappropriate attitudes and responses in the community and as users of services.

1.17 It has been suggested that around one in five adults in Scotland has an impairment and / or long term illness². Scotland's population is ageing, and life expectancy for men and women is expected to increase by around 6 years by 2031, by which time the number of men and women aged 75 and over will be 1.75 times the current level. The Scottish Council Foundation (SCF, 2005) estimated that, by 2021, there will be an additional 109,000 people in Scotland who are disabled, or have a limiting long-term illness. This will represent 22% of the population, compared to 19% at the time of the 2001 census. These changes will bring a series of challenges, not least that the numbers of people living in Scotland with impairments which require part- or full-time support will rise.

1.18 The need to enable independent living is not simply a matter of numbers. It is a human rights issue and is "a process of empowering people to exercise their human rights" (Zarb & Hasler, 2004). While the DDA 1995 granted a series of specific rights to disabled people in relation to employment and access to services, it has been suggested that many organisations have previously taken a deliberately minimalist approach to ensuring the rights of disabled people (ODI, 2005), characterised as doing "as little as possible" to avoid legal action. The Office for Disability Issues (ODI) also argues that, until recently, the onus

² For example, Scottish Council Foundation, 2005; Office for National Statistics, 2004; Inclusion Scotland, 2005; Scottish Executive, 2006a.

has been on disabled people to enforce their own rights in relation to independent living (as well as other issues), potentially meaning both that some will lose out (due to lack of knowledge) and that organisations are unlikely to be consistent (as progress is brought about by individual actions, rather than policy). It could also be argued that the DDA actually only provides the right to a remedy for discrimination

1.19 The implementation of the new Disability Equality Duty is, in part, designed to redress this, by placing the onus on public bodies to *promote* equality, as well as to remove unlawful discrimination. Previously, involving disabled people was good practice, now it is a legal requirement, enforceable by court action. This should make it much easier for disabled people to understand, and to ensure their rights, although there remain problems with rights being inadequately framed which have the potential to undermine independent living (Zarb, 2006). Zarb notes:

“The DRC believes that there should be a basic enforceable right to independent living for all disabled people.”

1.20 There are also positive economic and social reasons to promote and develop independent living, with a link to “Britain’s main public policy goals” (DRC, 2007a). It has been suggested (SQW, 2007), that investing in independent living can lead to a range of medium and long term economic benefits. For example, supporting disabled people to remain in work removes the need for work-related benefits, and generates tax revenues. Supporting disabled people to live at home, for example, through the use of Direct Payments, is more cost-effective than residential care through NHS or local authority sources. Zarb & Hasler (2004) state that:

“Increased participation not only benefits disabled people themselves but also produces economic benefits to governments, businesses and communities.”

1.21 The DRC (2007a) also notes that independent living has benefits for other groups, such as, for example, older people and those who provide informal support. It also has implications for gender equality, as many carers (both informal and paid) are women (DRC, 2006e). The achievement of independent living was also identified by some stakeholders in the Scottish Parliament’s review of equalities work (RHA, 2006a) as a priority for the future.

Independent living and particular groups

1.22 Throughout this report, it is recognised that disabled people have diverse personal experiences and that the support and changes required will vary. As Zarb (2006) stated:

“In reality, disabled people are customers, workers, students, parents, taxpayers and voters, and community members. The purpose of any form of support should, therefore, be to enable people to overcome the practical barriers they face to participating in all of these roles and activities.”

1.23 It is also recognised that there are groups of disabled people who may face particular issues which affect their independent living requirements. This might include, for example: people with particular impairments or health problems; disabled parents; people in work; women; LGBT people; ethnic minority people; older people; people in long term residential care; children and young people; people in some religious / faith groups; and others.

The key requirements for independent living

1.24 Independent living covers every area of life, and requires enabling disabled people to have access to a range of opportunities and a number of authors have identified key components of independent living. Gillinson et al (2005), for example, highlight “12 pillars or supports” for independent living. Others conceptualise the requirements in different ways, but the components identified generally cover a similar range of issues. This report identifies five broad areas which appear to have a key impact upon independent living, in which there is a need for appropriate provision. These are:

- The political, social and service structure.
- The environment / setting.
- Personal support and services.
- Opportunities for economic and social participation.
- Funding and resources.

The role of each in promoting independent living is considered below.

THE POLITICAL, SOCIAL AND SERVICE STRUCTURE

1.25 Independent living requires a political, social and service structure with appropriate arrangements to enable this.

The decision making structure

1.26 There is a need for a national and local decision making structure which is supportive of independent living. This requires appropriate mechanisms, forums and partnerships at a national and local level through which issues relating to disability and independent living (and equality issues more generally) can be considered by relevant organisations (such as, for example: the Scottish Parliament; the Scottish Executive and key agencies; disability organisations; local authorities; NHS bodies; partnerships; and voluntary and private sector organisations, including providers).

1.27 It is also important that individual organisations have appropriate mechanisms through which they can develop independent living. Clear links are required between the mechanisms for the consideration of independent living and other cross-cutting decision making structures.

Overarching policy and legislation

1.28 Within the overall decision making structure, it is also important that there is a commitment to independent living on the part of all relevant policy makers and service providers, and that this is reflected in legislation, policy and practice. There is a range of relevant policy, legislation, strategy and practice which impacts upon independent living, and which should actively promote this (and ensure that it does not constrain or militate against independent living). Independent living needs to be embedded in all legislation, policies, strategies and services (and reflected in targets, actions, milestones, outcomes inspection and audit).

1.29 It is important that policy and practice are based upon principles which support and sustain the focus on independent living, with a shared strategic approach based upon shared definitions, a clear vision and overall direction. The principles of independent living need to be well-understood and accepted by those who have a role in ensuring that these are reflected in practice. The achievement of independent living will be the responsibility of many and different service providers and clearly requires visible and accountable leadership from the highest

level, with identified responsibility for taking work forward, and links at an operational level between relevant organisations.

Inclusion and empowerment

1.30 A further aspect of an appropriate structure for independent living is the inclusion and empowerment of disabled people as equal partners at all stages and at all levels in the process. This was raised by disabled people in this study as a key issue and recognised in a report by the Prime Minister's Strategy Unit (PMSU) entitled "Improving the Life Chances of Disabled People" (PMSU, 2005). The Disability Equality Duty also places a legal obligation on public bodies to involve disabled people. The inclusion of disabled people's expertise and experience in the design, planning, delivery, inspection and review of legislation, policy and services can help to ensure that these reflect the commitment to independent living and are taken forward in ways which best meet the needs of disabled people.

1.31 This requires an appropriate structure for meaningful and equal involvement, as well as the use of appropriate and accessible procedures and good practice (in terms of issues such as arrangements, information and materials, support provision etc.). The PMSU report (2005) highlighted the need for disabled people to be involved from an early stage in policy and service development, and for this to take place on a systematic basis. This requires mechanisms for inclusion at a national and local level, and for capacity within organisations of and for disabled people.

Information, advice and advocacy

1.32 Related to this, it has been identified that independent living requires appropriate, high quality, independent information, advice and advocacy to be provided, to support disabled people to achieve choice and control (PMSU, 2005). The need for accessible information, advice and advocacy in all areas was identified by many disabled people in this research. It was suggested that this needs to be provided at the earliest stage, in order to enable disabled people to manage their own needs and services.

1.33 Gillinson et al (2005) identified the role of well-informed user-led organisations in providing "emancipatory services". Disabled people are enabled to identify their own needs, and to highlight those requirements which will enable them to live independently, and "realise" their rights

(DEMOS, 2006). There is also a specific need to support people in accessing services in new ways, and the ODI identified that strong support is fundamental to the success of Direct Payments (ODI, 2006).

1.34 It is also important that disabled people have access to other types of information, advice and advocacy by specialist and generic services, with information provided in appropriate formats and using appropriate media (Scottish Council Foundation, 2005). As Inclusion Scotland (2005) stated:

“Information is not a luxury. It is an essential tool in all our lives.”

1.35 The particular need for advocacy has been identified by the DRC in a discussion paper prepared as part of the Disability Debate, and the DRC notes that:

“For many disabled people, advocacy is a vital component of independent living.”

The particular importance of the provision of peer counselling was also highlighted by one of the organisations in this study.

Attitudes and behaviour

1.36 A further key component of the political and social structure for the promotion of independent living is appropriate public attitudes and behaviour towards disabled people. Overall, the Scottish Council Foundation (2005) stressed that, under the social model, public attitudes have a key role in, and can be the cause of, disability. They also impact upon behaviour, and, consequently, upon the daily experiences of disabled people.

1.37 Attitudes can affect: whether disabled people are included in opportunities; how their abilities are recognised; how they are treated (e.g. in public life, as colleagues, in leisure and arts activities, etc.). The Scottish Executive “Report of the Disability Working Group” (Scottish Executive, 2006a) stressed that negative public attitudes impact not only on individuals’ self-esteem, but also serve to exclude disabled people from participating fully in society. They also impact upon safety, for example in disabled people being targeted as a focus for hate crime. It has also been suggested that public attitudes to disability and

independent living limit disabled people's own views of their right to independent living (Gillinson et al, 2005).

1.38 It has been widely recognised (DRC, 2006a) that, for disabled people to achieve independent living, there is a need for appropriate attitudes and understanding amongst the wider public, disabled people themselves, and service providers, and this was recognised by respondents to this research.

1.39 The "Report of the Disability Working Group" (Scottish Executive, 2006a) noted that, where attitudes are based upon inaccurate stereotypes and assumptions, actions taken are likely to be inappropriate. The Scottish Council Foundation (2005) identified the importance of those planning and delivering services being aware of the social model, the rights of disabled people and the kinds of issues which they face. It is vital that services are provided by well-trained and skilled staff who understand the issues and concepts relating to independent living, and the implications of these for their own roles.

Cross-cutting service issues

1.40 There are some general issues which apply across all services (whether provided directly or commissioned from other providers). It is important, in creating an appropriate service structure for independent living, that disability issues are "mainstreamed" (i.e. reflected in all provision), with specific provision where necessary. It is also vital that services are accessible, coherent and co-ordinated, with joint working between services (Social Exclusion Unit, 2005), clearly defined responsibilities, and co-operative, flexible approaches. There is also a need for seamless support, rather than fragmented provision.

1.41 The achievement of independent living requires disabled people to have access to all services on an equal basis with other members of the community, and the views of disabled people in this study indicated the importance of appropriate service provision in supporting independent living.

1.42 It is important that individual services make a clear commitment to independent living and reflect this in their own delivery. Services need to ensure that they identify and develop opportunities and actions to promote independent living in policies and provision, and translate these opportunities into practice. The Social Exclusion Unit (2005) also highlighted the need for clear performance management. Service

providers' practices relating to the promotion of disability equality and independent living also need to be subject to oversight, scrutiny and inspection, within a clear overall framework.

1.43 The ways in which services are planned and provided are also important, as independent living suggests the need for disabled people to be enabled to take the lead in identifying their own needs and ways of meeting them. The PMSU report, "Improving the Life Chances of Disabled People" (PMSU, 2005) noted that, with appropriate support, such a process can include people with a wide range of impairments.

1.44 Services require to meet the needs of different groups, reflecting the range of individuals involved. One respondent to this research noted a need for support to the parents and families of disabled people moving to independent living. The PMSU report (2005) stated that the most effective service responses are those which are personalised.

THE ENVIRONMENT

1.45 The second broad area recognised as being required for the achievement of independent living is an accessible environment (DRC, 2006a). There are a number of components of this, and some of the group discussions and individual respondents in this study highlighted that individuals need access to different settings for different aspects of their lives, and must be able to use these, both inside and outside their homes.

1.46 The environment includes: the built environment (streets and pavements, shops, offices, other buildings etc); the transport system (to enable people to travel in the environment and to access economic and social opportunities); and the immediate environment of an individual's home. Without access to any one link, the opportunities for participation in economic and social life are constrained.

The built environment

1.47 An accessible built environment, free from barriers, in which disabled people can negotiate streets and buildings and have access to all outdoor spaces is a key requirement of being able to participate freely in all aspects of daily life (Inclusion Scotland, 2005). It impacts upon whether people are able to access goods and services (such as shops, banks, post offices, leisure centres, health services, libraries and other public buildings). It also affects access to employment and access to

leisure activities (in being able to use public spaces such as parks and countryside settings) and impacts on whether people can participate in social events (in pubs, restaurants, cinemas, theatres etc.).

1.48 The ability to participate in all of these ways is also linked to aspects of an individual's health and well-being. As such, there is a need to work with disabled people to address accessibility in the built environment, both in new developments and in improvements to the existing environment.

Transport

1.49 Transport is a further key element of being able to access a range of economic and social opportunities, and the Transport White Paper (Scottish Executive, 2004a) highlighted the importance of transport in enabling access to jobs, social activities and services etc., as well as recognising the impact of this on people's quality of life. As with the built environment, there is a link between the ability to travel and an individual's health and well-being. DEMOS (2006) identified that the lack of accessible transport has a negative impact upon a person's ability to seek, and take up employment, as well as impacting upon their access to other services and to social activities. Many reports identify that problems with access to transport can lead to various forms of social exclusion (e.g. Ryan, 2004; RHA, 2004; PMSU, 2005).

1.50 Along with other aspects of an individual's surroundings, therefore, transport is a key element of independent living, and consultees in the Scottish Parliament's Disability Inquiry (The Scottish Parliament, 2006a), stressed the importance of affordable, accessible and integrated transport. There is a need for services which meet the needs of individual users, and for access (in the widest sense) to a seamless and integrated network of all forms of transport (car; bus; ferry; rail; and air travel). Transport needs to be provided on an affordable and equal basis, with clear consideration of disability issues in all transport developments.

Housing

1.51 Disabled people need to have access to real choices about where they live and the type of housing which they occupy, to achieve independent living. Inclusion Scotland (2005) and the PMSU report (2005) noted that inappropriate or poor housing can increase the impact of an impairment, or be a causal factor in disability. Housing is important

for people to be able to take up education, employment and social / recreational opportunities while, conversely, the lack of accessible and suitable housing:

“... is a major barrier preventing disabled people living independent lives with access to all the opportunities most non-disabled people take for granted” (Inclusion Scotland, 2005).

There is also interaction between the home and the built environment, and the Scottish Council Foundation (2005) identified the importance for some disabled people, of being close to services.

1.52 There is a need for appropriate, affordable and accessible housing of a range of types in all sectors, including new build and existing housing. Housing services need to take account of disability issues, with disabled people having appropriate support to access housing and the housing stock managed in a way that provides choice and control for disabled people. Any required adaptations need to be made available and the housing maintained, as:

“Housing repair, improvements and adaptations help in keeping disabled people out of residential care as well as in preventing hospital admissions and delayed hospital discharge.” (ODI, 2006)

It is also important that policies in other areas, such as planning, income, community care etc. do not unintentionally constrain choice of location or house.

PERSONAL SUPPORT AND SERVICES

1.53 The third broad area identified for the achievement of independent living is appropriate personal support and services. Individuals may require support with various aspects of their personal lives, such as health, personal care, practical tasks etc. Disabled people in this study noted that, where this works well, it can have a positive impact upon independent living.

Health and community care services

1.54 The “Report of the Disability Working Group” (Scottish Executive, 2006a) identified the potential for community care and health

services, amongst other provision, to promote equality and social inclusion for disabled people. In terms of health services, the PMSU report (2005) stated that:

“A wide range of health services can make all the difference to whether someone can live independently, work, be a parent and participate in their local community.”

1.55 It is important, however, to stress that there is a complex relationship between disability and health. The “Report of the Disability Working Group” (Scottish Executive, 2006a), for example, noted that people with impairments may experience ill-health, but it is important not to confuse disability with ill-health, nor to see it in these terms. The report notes, however, that a person who has a chronic illness, and those with some forms of impairment which impact upon their health, may experience social barriers which cause disability. Some individuals require equipment which is provided by the NHS in order to address social barriers.

1.56 Some disabled people may also need personal care and personal support, and the DRC (2007) noted that:

“access to appropriate personal care is an essential means of achieving independent living.”

An event in Wales to discuss independent living also identified effective and appropriate personal assistance as being of key importance for some (DRC, 2006a). Although it is clear that individuals will require different types of provision, DEMOS (2006) identified forms of personal support which may be required. Generally, these might include: personal care; personal assistance; home care; technical equipment; and, potentially, other forms of provision to enable people to participate in other aspects of their lives (such as leisure, education etc.).

1.57 There is a need for a focus on independent living in all of the key developments and initiatives in health and community care, and for services to be aware of their role in this, with appropriate planning and delivery processes and procedures. The key issue in health and community care services is again to ensure that, in common with other members of the community, disabled people have access to services which address their personal needs, and that these services promote independent living.

Direct Payments and Independent Living Fund Grants

1.58 A closely related issue in the consideration of the provision of personal support is the need for disabled people to have choice and control of the ways in which personal support and services are provided to them (e.g. Scottish Council Foundation, 2005). This is seen to require a particular approach to purchasing community care (and, for some, a range of other forms of personal support and services), through methods such as Direct Payments. These enable people to purchase and manage themselves the services which they have been assessed as requiring (Riddell et al, 2006a). Independent Living Fund grants also enable people to purchase their own support.

1.59 Riddell et al (2006a) noted that the campaign for Direct Payments was “inspired” by the independent living movement and these have been widely recognised as helping to enable independent living and increasing choice³ or enabling a personalised response and an holistic approach to individuals’ needs (PMSU, 2005). A range of benefits have also been reported by service users⁴, including respondents to this research.

1.60 Given the importance of Direct Payments, independent living requires a robust, consistent and appropriate system for their implementation. Direct Payments need to be available to those who need them and well-funded, with appropriate support for users⁵.

OPPORTUNITIES FOR ECONOMIC AND SOCIAL PARTICIPATION

1.61 The fourth key component of independent living is the promotion of opportunities for participation by disabled people in all aspects of economic, social and public life, including: access to opportunities to gain, sustain and retain employment; to participate in education and training; to participate in leisure, social and public life; and to have access to an appropriate income. These opportunities are clearly linked

³ For example, Direct Payments Scotland, 2003; National Centre for Independent Living, 2006; Riddell et al, 2006a.

⁴ For example, Department of Health, Social Services and Public Safety, 2005; National Centre for Independent Living, 2006.

⁵ It is important, however, to recognise that, although the number of Direct Payments is rising, the proportion of people receiving these is a small fraction of the number receiving support from health or community care services, and the needs and requirements of those who receive services in ‘traditional’ ways remain important.

to an accessible built environment, transport system and housing, discussed above.

Employment

1.62 The need for employment opportunities has been widely recognised as an important element of independent living, both in terms of its impact upon the level of income which an individual will have, and its impact upon other factors such as self-esteem and social opportunities. (e.g. PMSU, 2005; Scottish Council Foundation, 2005). Inclusion Scotland (2005) stated that:

“... proper, fulfilling employment with prospects for self achievement and advancement is the best form of social and economic welfare.”

1.63 As well as providing benefits to individuals, the “Report of the Disability Working Group” (Scottish Executive, 2006a) notes the wider benefits to the economy and businesses of the employment and retention of disabled people. Similarly, Gillinson et al (2005) cite evidence from an employment project involving disabled people in Glasgow, which, across 15 participants, delivered a net economic benefit to the city estimated at £433,000. Conversely, where there is a low employment rate of disabled people, this is seen to be detrimental to the economy and to society as a whole (The Scottish Council Foundation, 2005).

1.64 In order to enable access to employment opportunities, there is clearly a need for a range of provisions, including: employment developments which reflect the needs of disabled people; support to enable people to gain access to employment; an appropriate workplace; appropriate working practices; and aids, adaptations and support, as required. Employers in Scotland need to recognise the potential contribution of disabled people to the workforce and provide opportunities to enable them to realise their contribution. Disabled people themselves also need to be encouraged and empowered to seek and obtain employment.

Education and training

1.65 Education and training are closely linked to employment, and are again central to independent living⁶, particularly in terms of their potential impact upon the choices available to disabled adults. As the Scottish Council Foundation (2005) noted, education is not only important for personal fulfilment, but also for accessing opportunities in the future, and its importance has been reiterated by many authors. Gillinson et al (2005) also highlight the role that training can play in removing barriers for disabled people.

1.66 Independent living requires an inclusive approach to education and training, with disabled people enabled to participate on an equal basis with non-disabled people in all forms of this. There is evidence of the benefits of inclusive education for disabled and non-disabled children (Sebba and Sachdev, 1997). It has also been identified as important to ensure appropriate provision at points of transition (Welsh Assembly, 2007). The achievement of independent living suggests the need for policy and practice to reflect this, and to increase the availability of opportunities for disabled people to participate throughout all forms of education and learning.

Leisure, social and public life

1.67 The importance of participation in leisure activities, social and public life is also recognised as an important aspect of involvement in society, and active citizenship. The ability to join in local community events and activities, as well as to have access to sport, arts activities, social networks and civic involvement are clearly components of the choice, control and freedom which are required for independent living. Inclusion Scotland (2005), identified the importance of enabling disabled people to participate in these types of activities, and the specific benefits of participation in volunteering, as a route to employment, have also been identified by the ODI (2006) and respondents to this research.

1.68 These facilities need to be accessible to disabled people (in the widest sense) on an equal basis. Disability issues need to be recognised and taken into account, in the provision and promotion of opportunities for leisure, social, public and civic participation which are barrier-free.

⁶ Issues relating to school education are not considered in detail in this report, as the focus is primarily upon disabled adults.

Income

1.69 The Scottish Council Foundation (2005) identified the importance of income in relation to overall quality of life. The level of income impacts upon issues such as: the choices which an individual can exercise; access to other goods and services, such as, for example, housing and transport; opportunities for participation in, and access to services and social networks (e.g. in terms of being able to access and use transport, as well as the ability to purchase goods and services and to join in social activities for which a payment is required). This is closely linked to education, training and employment, as people's experiences in these areas are likely to affect the level of income which they can achieve. Deprivation and poverty are linked to exclusion and poorer services.

1.70 Independent living requires a level of income for disabled people which recognises the costs which they face and which enables participation in other aspects of life. Additionally, as many disabled people receive benefits, it is important that the benefit system enables people to participate in the workforce where they can do so, and provides an appropriate level of income for those for whom this is not an option. Independent living needs a system which: recognises issues facing disabled people; makes provision which is sufficiently flexible to take account of their diverse individual circumstances; and recognises and meets the additional costs which may be incurred. There is also a need for continuing anti-poverty work, and for a focus within such work upon the issues facing disabled people.

FUNDING AND RESOURCES

1.71 The final broad area identified as a requirement for independent living (including by a number of participants in this research) is the provision of appropriate funding and resources to support and sustain this. It is well-recognised that the achievement of independent living, through addressing barriers and promoting new ways of supporting disabled people, requires adequate funding and resources, on a long-term, sustainable basis (e.g. DRC, 2006a; PMSU, 2005), with a number of aspects to this.

1.72 At a national level, there is a need for sufficient central government resources (existing and new) to enable the implementation of key changes and appropriate initiatives and actions to promote independent living. There are many policy areas and specific aspects of services which might be developed with such provision.

1.73 It is also important to identify independent living and disability equality as a priority in the allocation of resources by national organisations and agencies, and for these priorities to be reflected in local spending decisions. At a local level, it is important for existing and new resources to enable service developments to support and sustain independent living.

1.74 The provision of an appropriate infrastructure for independent living also needs appropriate resources (e.g. the development of information, advice and support; the development of the capacity of user-led organisations; the development of mechanisms for inclusion and empowerment of disabled people; and the development of disability equality training).

1.75 The PMSU report (2005) also noted the need for the effective targeting of existing resources. This requires consideration of ways of increasing the support provided to independent living developments from existing services, and can enable access to “mainstream society” and services, as well as supporting and sustaining existing networks of provision. It is also important to ensure that the need for independent living and disability equality are promoted in the commissioning of services. All of these funding provisions imply the need to recognise the benefits (including the economic benefits) of independent living.

OVERVIEW

1.76 Having identified the key requirements for independent living, the remainder of the report considers the current situation in relation to these issues (both positive and negative) before suggesting a number of opportunities for change. The following section examines some of the developments which have taken place in the UK and in Scotland in recent years, which may have had a positive impact upon, are relevant to, or have the potential to impact upon, independent living.

SECTION 2: SCOPING THE CURRENT CONTEXT

2.1 The first section identified the key areas which impact upon independent living as being:

- The political, social and service structure.
- The environment.
- Personal support and services.
- Opportunities for economic and social participation.
- Funding and resources.

2.2 This section focuses upon identifying examples of progress or relevant developments in each of these areas, before Section 3 examines some of the remaining barriers to independent living⁷.

THE POLITICAL, SOCIAL AND SERVICE STRUCTURE

2.3 It is important to consider the overall structure for the promotion of equality for disabled people, the structures in key policy areas and the overall social context for the promotion of independent living.

The decision making structure

2.4 There have been some key developments to the decision making structure in Scotland which impact upon independent living. Overall responsibility for equal opportunities and related primary legislation rests with the UK Parliament at Westminster, as this is a reserved matter, but responsibility for legislation in many of the specific policy areas which impact upon independent living is now devolved⁸. These arrangements clearly impact on the ways in which change can be achieved, and are considered further later.

2.5 The Scottish Parliament has a general role in encouraging and promoting equal opportunities and has a mandatory Equal Opportunities Committee with a remit to consider and report on matters relating to equal opportunities within and outwith the Parliament. Additionally, it can impose duties on Scottish public authorities and cross-border public

⁷ It is important to note that the developments highlighted are those which should be relevant to independent living, although it is not necessarily the case that they will have had an actual impact on this in practice.

⁸ Although employment and benefits, for example, are reserved.

authorities in relation to their Scottish functions (RHA, 2006a). Equal opportunities is one of the founding principles of the Scottish Parliament, and it has adopted a mainstreaming approach.

2.6 The Scottish Executive also has a role in promoting equality. An Equality Unit considers policy and practice issues, and issues relating to the Scottish Executive as an employer. A wide range of departments (such as health and education) are involved in areas relevant to independent living, as are agencies such as Communities Scotland.

2.7 There are a number of ways in which the Scottish Parliament and / or the Scottish Executive undertake work of relevance to independent living, including through⁹:

- Identification and adoption of principles.
- Legislation on relevant issues.
- Provision of guidance and leadership on equalities issues.
- Oversight of the implementation of UK legislation.
- Consideration of wider relevant issues through, for example, cross-party working groups and inquiries.
- Development of strategic work addressing equality.
- Provision of funding to address specific issues.
- Standard setting and scrutiny.

2.8 The DRC is also an important part of the overall structure in Scotland, and was established in 2000. It has a statutory remit to eliminate discrimination, and promote equality for disabled people. It has a wide range of functions, including: providing information, guidance and advice; formal investigations; taking legal action; and supporting individual disabled people to secure their rights. It also campaigns to highlight and address issues relevant to disability, including considerable work in the area of independent living.

2.9 A range of voluntary organisations also have a key role in promoting equality for disabled people. At a national level, the Scottish Council for Voluntary Organisations (SCVO) represents voluntary organisations on a wide range of issues. The Scottish Disability Equality Forum (SDEF) and Inclusion Scotland are national organisations of and for disabled people. There are also many impairment-specific national organisations working with particular groups of disabled people (e.g. Capability Scotland, RNID, RNIB, ENABLE Scotland, and others). At a

⁹ Some of which were identified in RHA (2006a).

local level there are area-wide forums of disabled people, organisations such as the Glasgow and Lothian CILs and other specific local groups.

2.10 Local arrangements for consideration of equalities issues vary across Scotland. Responsibility for the implementation of national policy and delivery of local services rests with local authorities, NHS bodies and a range of national and local voluntary organisations. Community planning (and other) partnerships, which bring together local stakeholders also have a key role in this.

2.11 A recent review (RHA, 2006a) highlighted a range of ways in which the Scottish Parliament, the Scottish Executive and others have taken equalities work forward since devolution. The report suggested that there have been some positive developments to the promotion of equality, and these are clearly important in moving towards independent living.

Policy and legislation

2.12 Alongside structural changes, a number of overarching legislative and policy developments have had an impact on disability equality and independent living, and are likely to continue to do so. Overall, there has been an increasing recognition of the need for a rights-based approach to disability equality (Gillinson et al, 2005) and this is reflected in some policy developments. At a European level, the Council of Europe and European Commission have identified independent living as an important way of making sure that disabled people participate fully in society (DRC, 2007a).

UK-wide

2.13 At a UK level, the Disability Discrimination Act 1995 (DDA) gave disabled people rights in relation to employment; education; access to goods, facilities and services; and buying or renting land or property. It also required 'reasonable adjustments' to be made to enable disabled people to be able to access goods and services. In April 2005 a new Disability Discrimination Act was passed by the UK Parliament, amending or extending provisions in the DDA 1995.

2.14 Since December 2006, public bodies in Scotland have had a duty to actively promote disability equality and the public sector must have due regard to the need to: promote equality of opportunity for disabled people; eliminate unlawful discrimination against disabled people;

eliminate harassment; promote positive attitudes; encourage participation; and take steps to meet disabled people's needs. A total of 264 public bodies are covered by the statutory duty to promote disability equality. Along with other requirements, they have a specific duty to develop a disability equality scheme (covering a three year period), with annual reporting, and disabled people being directly involved in the drafting and review of the schemes.

2.15 In relation to independent living, it has been suggested that the recognition of the need for positive provisions to address discrimination (rather than treating everyone "the same") and the need to "promote equality at an institutional level" have been important developments.

2.16 The Equality Act (2006) created a new "Commission for Equality and Human Rights" (CEHR) which will be established in 2007 and will draw together the 6 "strands" of equalities work, focusing on the promotion of equality and human rights. The work of the DRC will be subsumed into the CEHR from October 2007.

2.17 As well as legislation, there have been relevant strategic UK developments, including the publication of the report "Improving the Life Chances of Disabled People" (PMSU, 2005). This focused strongly on the need to promote independent living, and saw this as the way forward in supporting disabled people in the future, identifying a vision that:

"by 2025 disabled people have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society".

2.18 The Government accepted the recommendations of the report, including the establishment of a Task Force on Independent Living and a national Office for Disability Issues. The ODI has a co-ordinating role in taking forward developments in areas reserved to Westminster and works with the Scottish Executive to take forward developments in devolved areas. There is also a cross-governmental Ministerial group meeting quarterly, with parallel arrangements for senior officials. An Expert Panel has been established to consider independent living issues.

2.19 The recommendations relating to reserved issues will be implemented across the UK and will affect the development of work in Scotland in the future. The report suggested that the relevant administrations should consider actions relating to devolved issues.

Future ODI reports will consider how the agenda is being pursued in areas of devolved policy responsibility. A 2006 report “Delivering Independent Living in Wales” (Stirling, 2006) identified some opportunities for a devolved administration to contribute to enabling independent living developments.

2.20 In July 2006, the ODI was asked to undertake a review of independent living¹⁰, with three main study areas: the nature and extent of barriers; the resources and support involved; and the effectiveness of the delivery of these resources. Its recommendations are expected by Summer 2007.

2.21 The DRC set out its agenda in 2005, and has been involved in strategic work to take independent living forward. The “Disability Debate” (published as the Disability Agenda) included identifying the importance of independent living, and the publication “Changing Britain for Good – Putting Disability at the Heart of Public Policy” also identified the following particularly relevant priorities:

- *Ensuring that no one is obliged to live in an institution or particular living arrangement against their will; and*
- *Securing rights and entitlements which facilitate independent living across the life course.*

2.22 The DRC also worked alongside Lord Ashley of Stoke to prepare the Disabled Persons (Independent Living) Bill, which received its second reading in the House of Lords in December 2006. The Bill aims to strengthen the rights and entitlements to independent living for disabled people (DRC, 2006e) in England.

Scotland

2.23 Key aspects of the UK-wide legislation apply in Scotland. In the case of the DDA (2005), there are also specific regulations relating to Scotland in the form of the Disability Discrimination (Public Authorities) (Statutory Duties) (Scotland) Regulations 2005. These set out the form, nature and timing of Disability Equality Schemes, and specify the public bodies required to prepare these. Scottish Ministers have a duty to publish reports every 3 years (from 2008), with information about progress and future action.

¹⁰ This covers England only.

2.24 The CEHR will have a Disability Committee, and a Scotland Committee, and one of the Commissioners will have a remit specific to Scotland. The Government has made it clear that the promotion of independent living will be included in the activities of the CEHR (DRC, 2007a). The DRC has also recognised a “strong connection” between the CEHR’s “Outcomes for Society” and independent living. Zarb (2006) also suggested that there are “encouraging signs” of potential to use European Convention rights to support some aspects of independent living.

2.25 A representative from the Scottish Executive is a member of the team taking forward the PMSU recommendations. One of the recommendations of the Scottish Parliament report “Removing Barriers and Creating Opportunities” (2006a) was the establishment of an Independent Living Task Force in Scotland. The Scottish Executive has stated that it will consider what mechanisms need to be established, and will take into account the views of the Parliament. The Scottish Executive also noted plans to establish a Public Sector Equality Forum in Scotland (Scottish Executive, 2006c).

2.26 Other relevant overarching legislation in Scotland includes:

- The Scotland Act (1998) which established the Scottish Executive and Scottish Parliament. It defined equal opportunities in a Scottish context and set out the ways in which reserved and devolved powers would interact. Under the Act, Scottish Ministers and the Scottish Parliament need to ensure that they act in accordance with European Convention rights.
- The Scottish Commission for Human Rights Act 2006, which sets out in detail the functions and powers of the CEHR in Scotland, which extend only to those areas outside the competence of the Scottish Parliament.
- The Local Government in Scotland Act (2003), where Section 21 provides local authorities with the power to do anything they see fit (within the limits of the law and guidance issued by Ministers) to promote “well-being” in their area and for the persons within it. Most of the examples of this could include, or could be extended to include actions to improve the lives of disabled people.
- The National Health Service Reform (Scotland) Act 2004, which extended this approach to health bodies (as well as Scottish Ministers), to promote “health improvement”. This was explicitly

designed to promote innovation and local delivery, and would include actions to improve the lives of disabled people.

2.27 There have also been relevant overarching strategic developments and commitments in Scotland in recent years. For example, the “Partnership for a Better Scotland” agreement, setting out the current programme for the Scottish Parliament, committed the government to delivering “*a Scotland where everyone can enjoy a decent standard of life*”. The main commitments are through “Closing the Opportunity Gap”, the successor to the original Social Justice Strategy, which sets out measures to increase opportunities for disadvantaged groups in areas such as employment; education; financial inclusion; regeneration of neighbourhoods; health; and access to services.

2.28 There have been some key disability reports in recent months. The Equal Opportunities Committee of the Scottish Parliament carried out a “Disability Inquiry” which focused on access to work, further and higher education, leisure and the arts, and the report was published in 2006 (The Scottish Parliament, 2006a). Many of its recommendations are directly relevant to the promotion of independent living in Scotland. The Scottish Executive established a Disability Working Group in 2004 which reported in 2006 (Scottish Executive, 2006a) and also made a number of relevant recommendations, many of which have been accepted.

2.29 The DRC in Scotland has also been involved in promoting disability equality and independent living. The “Disability Debate” has been continuing and the “Disability Agenda” has recently been published and will inform the future work of the CEHR. The DRC also produced 10 priorities for action in 2006 (DRC, 2006c) which are relevant to promoting rights and addressing barriers which are relevant to independent living.

2.30 There is also some evidence of the growing acceptance by some organisations of the social model of disability. For example, some public bodies provided examples of their Disability Equality Schemes to this study, some of which set out and adopted this. The Scottish Parliament’s Equal Opportunities Committee and the Scottish Executive’s Disability Working Group also accepted this model, although it has been suggested that there may be tensions for some organisations, such as the NHS, in working to this.

2.31 It is also clear that some public bodies have, over the last 5 years, developed equality proofing tools. One local authority, for example, identified a “Corporate Equality Impact Assessment” tool, based on guidance from the DRC and the other commissions, which focuses on potentially negative impacts and “missed opportunities” to promote equality. Some authorities are focusing on current and future policies in their use of proofing tools. Many national and local organisations led by disabled people are also involved in a range of ways in developing both policy and practice.

Inclusion and empowerment

2.32 There has been a growing commitment in Scotland to exploring the views of disabled people (The Scottish Council Foundation, 2005). An exercise is under way involving the development of proposals for mechanisms for longer term engagement with the disability sector, although this is not yet complete (Scottish Executive, 2006a; 2006c). There are also existing mechanisms through which there has been consultation with, and involvement of, disabled people.

2.33 The National Standards for Community Engagement (Communities Scotland, 2005), identify that public bodies at all levels should ensure that they work closely with community groups, including disabled people, in developing policy and practice, removing barriers to engagement. A number of local authorities provided information about the ways in which they have developed consultation with, or involvement of disabled people, and one, in its Disability Equality Scheme, set out that it will consult with the “whole community” and not “those who shout loudest”. There are also various consultative forums relating to particular service areas.

2.34 At a UK level, following the PMSU report, a national forum (Equality 2025: the United Kingdom Advisory Network on Disability Equality) is being established by the ODI. This will enable input from organisations of disabled people to legislation, policy and practice, and will have a role in the work of the ODI.

2.35 The requirements of the Disability Discrimination Act (2005), specifically those relating to Disability Equality Schemes and the means by which these are developed and monitored, are likely to increase the involvement of disabled people in shaping policy and practice in Scotland in the future. The DRC (2006d) has developed guidance for public bodies about how they should involve disabled people directly,

and this provides an opportunity for further meaningful inclusion in developments.

Information, advice and advocacy

2.36 The report “Improving the Life Chances of Disabled People” (PMSU, 2005) identified that the most common services provided by organisations of and for disabled people are information, advice and advocacy. Disability-led organisations have a strong role in this, and in reaching marginalised groups. The report notes that a growing number of local disability organisations in England have service level agreements with their local authorities to provide such support.

2.37 Some organisations provide general support with a range of disability issues, while others provide more specific support with, for example, Direct Payments. Centres for Independent Living (CILs) provide specific support to enable disabled people to use Direct Payments (as well as offering information, training and policy expertise on independent living), and there are two in Scotland (in Glasgow and Edinburgh). UPDATE (an on-line information service) provides access to a series of leaflets and booklets on Direct Payments (and other issues) and there are other forms of information and support, some led by disabled people, some provided directly by local authorities or the Scottish Executive.

2.38 Some specialist advice relating to particular services is also available through, for example, Traveline and Disabled Persons’ Housing Services (which are available in a number of areas). There are many local projects providing generic and specific support to disabled people, for example in terms of advocacy or representation, and a number of areas have established community care, or disabled people’s resource centres. These provide a wide range of facilities and services directed towards enabling disabled people to live independently. In most areas, there are also representative groups of disabled people, or forums and networks which allow for information sharing and joint action. Generic advice and information are also available from organisations such as Citizens Advice Bureaux and Money Advice Centres (and community law centres, where these exist).

2.39 There are several pieces of current legislation relevant to Scotland which refer to independent advocacy, and there are 100+ independent advocacy organisations working in Scotland (Scottish Independent Advocacy Alliance, 2007), most of which are supporting

people to live independently. It was suggested in this study, however, that many of these work specifically with people with learning difficulties, and there are relatively few working with other groups of disabled people. The Scottish Executive response to the Disability Working Group report (Scottish Executive, 2006c) accepted a recommendation relating to supporting independent advocacy services for disabled people nationwide and undertook to investigate this further.

2.40 The findings of evaluations of support provision by user-led organisations have indicated that these are popular with service users and can be cost-effective. A study of intensive support schemes by the NCIL found that these helped local authorities to reach some marginalised groups and identified these as enabling many people to access Direct Payments who would not otherwise do so (Luckhurst, 2005). Barnes and Mercer (2006) suggest that support plays a critical role in helping disabled people achieve successful outcomes from Direct Payments. Many examples of the value of disability organisations in giving advice, information and support were highlighted in this research.

2.41 Steps have also been taken to improve the manner in which information is provided to disabled people. The Scottish Accessible Information Forum (SAIF) promotes the right to accessible information and has developed “Standards for Disability Information and Advice Provision in Scotland”. At a local level, Fife Independent Disability Network (FIDN), for example, developed a guide specifically for care home staff in meeting the communications needs of residents (FIDN, 2006). Many local organisations have developed their own accessible information, and other aspects of good practice. Agencies across Lothian developed a Lothian Inclusive Communication Policy in response to demand from people with communications difficulties, taking a rights-based approach to meaningful communication with this group.

Attitudes and behaviour

2.42 It has been shown that members of the public in Scotland are unlikely to express negative views of disabled people (Bromley and Curtis, 2003). There is some evidence that general perceptions of disabled people are improving (RHA, 2006b), and, generally, there was a view among many group participants that this is the case. This is important in making progress towards independent living (although, as will become clear in Section 3, there is still a long way to go).

2.43 Some campaigning work has been carried out, such as a “See Me” campaign funded by the Scottish Executive, which seeks to address the stigma associated with mental health problems. There has also been a UK Government “Images of Disability” initiative, seeking to improve the ways in which disabled people are represented in government publications, in the wider media, and in the numbers of disabled people featured in campaigns, with some success (DWP, 2006b).

2.44 There has been an increased provision of disability equality training in recent years, and this can be an effective way of increasing understanding and shifting attitudes, as well as leading to changes in working practices (Scottish Executive, 2006a). A number of organisations have been involved, and examples of disability equality training and disseminating practice information were provided to this research. One health authority, for example, indicated that all staff were to be “expected to attend disability awareness training” and one local authority provided examples of disability equality training being offered to procurement staff (in addition to the insertion of equalities requirements in contracts)¹¹. The health authority had promoted its Disability Equality Scheme through a newsletter, posters, the intranet with links to external bodies, briefings and drop-in sessions.

2.45 The Scottish Executive response to the Disability Working Group report (Scottish Executive, 2006c) noted that disability and citizenship materials will be considered in the context of Personal and Social Development and Personal and Social Education in schools. There is also “A Curriculum for Excellence” which encourages responsible citizenship. These have the potential to impact upon public attitudes in future generations. It is also likely that, through time, the implementation of the Disability Equality duty to promote positive attitudes towards disabled people will have an impact upon perceptions of disabled people.

2.46 There is also strong support in Scotland for action to tackle hate crimes (DRC, 2006c) and there has been a great deal of action to develop community safety and address anti-social behaviour in Scotland following the Anti-Social Behaviour Scotland Act 2004. At a local level, Community Safety Partnerships have developed strategies to address

¹¹ Terminology can be problematic in this area, as many organisations do not adequately distinguish disability equality training (which is generally value-based) from disability awareness training (which is not).

anti-social behaviour, and a wide range of initiatives are now in place, some of which are relevant to disabled people.

2.47 Inclusion Scotland (2005) identified the impact of the media upon attitudes in society. There is a “Broadcasting and Creative Industries Disability Network” enabling major UK broadcasters to come together to consider disability issues and share best practice (PMSU, 2005). Ofcom has a responsibility to have regard to the needs of disabled people when it carries out its functions, and to promote equal opportunities, with a committee to advise on disabled people’s interests. The National Union of Journalists in Scotland (NUJS) has produced a guide entitled “The Reporting of Mental Health and Suicide by the Media” (NUJS, 2006).

2.48 Gillinson et al (2005) suggest that there have also been developments in attitudes amongst disabled people, with the growth of user-led organisations increasing disabled people’s awareness of possibilities. There have also been campaigns aimed at disabled people, such as an initiative launched by the DRC in Autumn 2006 to help disabled people to become more confident in using public transport (with potential knock-on benefits of increased demand and accelerated provision of accessibility).

Cross-cutting service issues

2.49 There have also been some cross-cutting developments affecting service provision in the public, private and voluntary sectors. For example, it is clear that the DDA has, and will increasingly have, a major impact upon service providers and the DRC has issued a significant amount of guidance to the public and private sectors on how best to address changes and how to involve disabled people. Other aspects of this are also being taken forward by UK Government and Scottish Executive departments.

2.50 A further relevant cross-cutting issue for services is that the Scottish Executive is committed to a process of public service reform, with a key aspect of this being “personalising services around the needs of users”. In the paper on independent living produced as part of the Disability Debate, the DRC note the increased emphasis on choice and control by members of the community in the “design, delivery and evaluation of services”. The “Report of the Disability Working Group” (Scottish Executive, 2006a) identified that an independent review of scrutiny of public services has been announced, which will consider improvements to inspection, regulation, audit and complaints handling.

There is also an increasing emphasis on considering the impact of services on users' life experiences. Work has also started on considering a framework for auditing the Disability Equality Duty (Scottish Executive, 2006c).

2.51 The Scottish Executive is running a "Multiple and Complex Needs" initiative from 2006-2008 which aims to improve public services for people with multiple and complex needs who have difficulty accessing services and are described as "some of the very hardest to reach in society". Funding is being provided from the "Closing the Opportunity Gap Fund" to examine how different services can meet multiple and complex needs more effectively.

2.52 Some recent reports also have cross-cutting implications for service provision. For example, the Scottish Executive (2000b) published a report entitled "The Same as You? A Review of Services for People with Learning Disabilities" which made a number of recommendations about improving access to a range of services for this group. In the same year, a report of the Strategy Forum: Equipment and Adaptations entitled "Equipped for Inclusion" (Scottish Executive 2003e) made a number of recommendations, and work is being undertaken to improve statutory sector provision of equipment and adaptations (Scottish Executive, 2006c).

2.53 Many public bodies are also seeking to improve their approaches to developing equality and have tried to embed equalities issues within their approach to contracting and service level agreements. Some, for example, try to ensure that potential contractors have equalities policies in place, and seek binding commitments in relation to employment and other practices.

2.54 It should also be noted that a myriad of local strategies have been developed which are relevant to independent living. Sometimes these relate to services, or parts of services, and sometimes to particular groups of service users. It is clearly impossible to detail these, and the many other developments to practice in individual services which have taken place, but a range of examples of progress were provided (including one local authority highlighting the value of political support, investment and re-prioritisation in enabling improvements to provision).

THE ENVIRONMENT

2.55 Some significant improvements in the environment can also be identified, along with opportunities for further development.

The built environment

2.56 Responsibility for addressing issues in the built environment is shared between the UK Government, Scottish Parliament and local authorities. Owners of buildings also have responsibilities for their accessibility. While the DDA (1995) sets out a national framework for access, much of the detailed guidance and delivery is undertaken through the devolved planning system.

2.57 Access panels, made up of local disabled people acting on a voluntary basis, exist in most areas to provide advice on accessibility of new applications and existing sites to local authorities and developers. The Scottish Executive recently funded the SDEF to provide national support to local access panels, as well as becoming the main route for the distribution of funding.

2.58 In terms of legislative provision, Part III of the DDA 1995 made it unlawful for providers of goods, facilities and services to discriminate against disabled people and, since 2004, service providers have had a duty to make “reasonable adjustments” to their physical settings to ensure that disabled people are not excluded. The DRC (2003b) note that this has raised the profile of the need to improve access to the built environment with both employers and service providers.

2.59 The Scottish Executive Development Department (responsible for this area of policy and for the Scottish Building Standards Agency) has as a key priority for 2006-9 “ensuring planning and building standards legislation contribute to the delivery of a more inclusive built environment” (Scottish Executive, 2006g). There is also a Scottish Executive Planning and Building Standards Advice Note (PAN 78) which focuses on inclusive design and considers how to improve the design of places in order that they can be used by everyone, including disabled people (Scottish Executive, 2006f). The note highlights the importance of going beyond the minimum regulations.

2.60 With the Planning etc. (Scotland) Act 2006 there is a requirement for a statement to accompany planning applications setting out how access for disabled people has been addressed, going beyond the

issues covered in the building standards. Changes to building regulations which are due to come into force in May 2007 should lead to further improvements in the accessibility of buildings, and to the safety and amenity afforded to disabled people (SBSA, 2007).

2.61 The Department for Transport has published a good practice guide on “Inclusive Mobility” (Department for Transport, 2002), which sets out guidance on a wide range of issues, such as the design of ramps, street furniture, dropped kerbs etc.

2.62 There are also some examples of increasing recognition of issues for disabled people in the built environment by those involved in such work. The “Report of the Disability Working Group” (Scottish Executive, 2006a) identified that some architecture schools in Scotland have included disability equality training in their programmes, with plans to share their practice with other courses for professionals who can influence the accessibility of the physical environment (e.g. surveying, planning, product design). One local authority which responded to this research identified that it had recognised the impact of environmental factors on disabled people and had prioritised street lighting repairs for this reason. There have also been access improvements to many buildings.

Transport

2.63 There have also been legislative and other developments to the accessibility of transport in Scotland in recent years (RHA, 2004). The provision of transport is complex in terms of the location of responsibilities in Scotland, with some functions which are reserved and some which are devolved. Some rest with local government and some with transport operators themselves. A “Mobility and Access Committee for Scotland” (MACS) exists to provide advice to ministers and promote accessibility issues relating to transport. There are 7 regional transport partnerships covering Scotland, each covering a number of local authority areas and each has a responsibility to address transport issues for disabled people.

2.64 The rights of disabled people in relation to transport are reserved, and a number of UK-wide legislative changes impact upon this. Part III of the DDA (1995), relating to the duty of service providers to remove barriers making it impossible or unreasonably difficult for disabled people to use services applies to the infrastructure for public transport. Part V sets out detailed requirements and timetables for transport

vehicles to be made accessible to most disabled people, and, as specified in Part V, accessibility regulations have been introduced by the Department for Transport to ensure that all new rail vehicles, buses and coaches are accessible to disabled people (see ODI, 2006 for a summary).

2.65 Additionally, transport operators (with changes to the DDA in 2005) are required to make sure that disabled people receive fair treatment, and the DRC has produced a Code of Practice to assist them in understanding their new duties. One respondent to this research noted that they had used the DDA to improve access to a railway station, and one of the group discussions suggested that “mystery shopper” exercises by First Scotrail had been positive. In early 2007, the DRC launched a campaign to encourage disabled people to use public transport, and to realise the rights which have been provided with the recent legislative changes.

2.66 Responsibility for rail services and for specifying track and infrastructure improvements is now devolved, and there is a national agreement for all train operating companies and Network Rail to provide a seamless service to disabled people. There is also a national train booking service for disabled people. Network Rail has been authorised to spend an annual amount on station improvements (The Scottish Parliament, 2006a). The Scottish Executive also has responsibility for most aspects of the regulation of buses, taxis and ferries (although not aeroplanes), but not their accessibility. Local authorities can (and many have) specified either that all new taxis, or all existing and new taxis, must be accessible to certain groups of disabled people.

2.67 There is also a Disabled Persons Parking (Scotland) Bill currently in a consultation period. This would prevent people from abusing parking spaces designated as accessible bays reserved for disabled drivers, by making them legally enforceable, with standardisation across Scotland (BBC News, 21/11/06).

2.68 There have also been developments to concessionary travel in Scotland, and, since April 2006, this has been extended to cover bus travel over the whole of Scotland for certain eligible groups of disabled people. A range of other concessions and subsidies apply covering different modes of transport such as rail, ferry and taxis, and these vary across local authorities and operators.

2.69 A Transport Strategy for Scotland was published in December 2006, which makes clear the problems facing disabled people in using all forms of transport. Improving the accessibility of public transport (within the framework of the DDA) and improving the existing concessionary fares schemes are key priorities. There are also regional and local transport strategies covering local transport issues, and Scottish Executive guidance makes clear that these should address access issues. Equality considerations are also a core principle in the Scottish Transport Appraisal Guidance analysis carried out on transport projects.

2.70 Many local authorities have put in place improvement programmes designed to address access issues at bus and rail stations and, again, there are many other examples of local action to improve transport which cannot be detailed here.

Housing

2.71 Housing is a devolved responsibility in Scotland, with a wide range of agencies involved, including the Scottish Executive, Communities Scotland, social landlords and local authorities, as well as private sector builders. A large proportion of what has been termed “special needs” housing in Scotland is funded by Communities Scotland, working in partnership with local authorities and housing associations, and there has been a rise in the amount of this in the last 30 years (Scottish Council Foundation, 2005). Responsibility for the provision of adaptations to housing is split between the local authority (social work and housing services) and health (acute and primary care services). Those which meet “social” need are provided via the local authority and those meeting nursing need are the responsibility of health services.

2.72 Disabled Persons Housing Services (DPHS) provide assistance to disabled people about rights and options. These are publicly funded and user-led, with disabled people generally making up a majority of board members and staff. Services vary by location, but advice, information and advocacy are common, together with the management of databases of accessible property and disabled people in housing need.

2.73 Those providing housing in Scotland must work within the planning and development criteria which are set by a local authority (Inclusion Scotland, 2005) and all housing support services must register

with the Care Commission under the Registration of Care (Scotland) Act 2001.

2.74 Amongst key legislation is the Housing (Scotland) Act 2001, which:

- Identified the housing needs of disabled people as a key priority, with a commitment to improving physical living conditions.
- Introduced new rights for disabled people and changes to the provision of assistance for improvements. It enabled grants to be made to local authorities for housing support services and for secondary legislation and guidance to specify the use of the grant¹².
- Required that information be collected about the number of people requiring adapted housing and the number of accessible properties which are available¹³.

2.75 The Homelessness (Scotland) Act 2003 increased the likelihood of disabled people presenting as homeless having their applications accepted and receiving assistance (Doherty, 2006). Disabled people, and families where a member is disabled, are currently regarded as being in priority need when presenting as homeless, and qualify for assistance and the provision of accommodation.

2.76 The Disability Discrimination Act 1995 made it unlawful for those disposing of, or managing properties to discriminate against disabled people, for example in terms of accepting applications for housing, the management of waiting lists or a refusal to agree to a let (or to do so on less favourable terms). Under the DDA (2005), those letting or managing property must make 'reasonable adjustments' to policies, practices, procedures and terms that prevent a disabled person using or enjoying rented facilities. This includes providing auxiliary aids or services.

2.77 The Housing (Scotland) Act 2006 contains provisions to improve the quality of private sector housing. New regulations and guidance will be prepared by Communities Scotland and the Scottish Executive to

¹² It is a standard condition that Communities Scotland grant funded housing should be designed to "Housing for Varying Needs" standards, adopting the barrier free principle wherever possible.

¹³ Since then, further developments have allowed disabled people to search for adapted and accessible properties, and make contact directly with housing providers offering them.

support the changes, which will be implemented by local authorities and others. Grants for repairs and adaptations for homeowners and private tenants in Scotland have been available from local authorities, and amongst the changes under the Act is a new “Scheme of Assistance” to give householders access to a wider range of funding, support and information to help them to improve the condition of their homes (including making housing accessible for disabled people). The Act also introduces new rights for disabled tenants in private rented accommodation.

2.78 All local authorities are required to have homelessness strategies, and have a range of other policies relevant to homelessness. Authorities are also required to assess housing needs and provision in their area and prepare a local housing strategy. The assessment is required to cover the need for, and availability of housing for people with “special needs”. Some local authorities provided examples to this research of the inclusion of these issues (although there appears to be some variation in how they are considered and expressed in housing and homelessness strategies).

2.79 In addition to these requirements, the “Partnership Agreement” in Scotland expressed a commitment to ensuring that more homes are barrier-free, and the concept of enabling people to live in their own homes has been emphasised in a range of documents from the Scottish Executive (Communities Scotland, 2004).

2.80 A “Supporting People” programme was introduced in 2003, which provides housing support for “vulnerable” people in Scotland, including disabled people, to live independently in the community, and provides a planning and funding framework for housing-related support services (which might include, for example: general advice; help with budgeting or shopping; home safety; assistance with administrative issues). Local authorities are required to review all of their Supporting People services by the end of March 2007 (part of which involves assessing their “strategic fit” as well as ensuring value for money and good quality services). The potential impact of these, and other housing developments upon independent living is clear.

PERSONAL SUPPORT AND SERVICES

2.81 The third broad area of relevance to independent living is the provision of personal support and services. As in other areas, there have

been changes to this which are relevant to the development of independent living and offer further opportunities for change.

Health and community care services

2.82 Many local health and community care services are routinely accessed by disabled people, and these services are considered together, as their delivery to individuals is often closely linked. Many (such as GP services), are not specific to disabled people, while some (such as home care services) are “shared” with other groups, and others are more specialised. The provision of health and community care services is the devolved responsibility of the Scottish government, and the Scottish Executive has overall policy responsibility, working through a complex network of NHS, local authority and voluntary sector bodies.

2.83 The lead responsibility for assessing local need and providing and co-ordinating community care services rests with social work departments of local authorities (although services can be provided by, and commissioned from, other services such as housing associations, health authorities, voluntary and private sector providers). The lead responsibility for assessing health services lies with NHS bodies (although the distinctions are increasingly blurred, as health and community care providers work more closely together). Most areas have a Community Care Forum (or similar), generally made up of representatives of public and voluntary sectors, and usually with sub-groups dealing with different groups of service users.

2.84 A number of legislative developments impact upon health and community care services in the context of independent living. For example:

- The general provisions of the DDA 1995 apply to health and social work service providers, and most health and social care facilities have been made physically accessible to most disabled people, with developments in, for example, communication and information provision and wider disability awareness.
- The Community Care and Health (Scotland) Act 2002 provided for the expansion of joint resourcing and joint working between NHS Scotland and local authorities in terms of services relevant to community care.
- The Health White Paper, “Partnership for Care” (Scottish Executive, 2003a) outlined the future direction of the health

service in Scotland and emphasised the importance of partnership, integration and the redesign of the service to reflect such principles.

- The National Health Service Reform (Scotland) Act 2004 led to the creation of Community Health Partnerships (CHPs) and placed a further emphasis on joint approaches to health and social care.
- The Community Care and Health (Scotland) Act 2002 enhanced the rights of informal carers.
- The Registration of Care (Scotland) Act 2001 set out that all social care and housing support services must register with the Care Commission.
- The Adults with Incapacity Act (2002) set out provisions to allow adults to exercise more decision making and autonomy.

2.85 There are also a number of relevant strategic and policy commitments. For example, in 2003 the Scottish Executive published a framework document “Improving Health in Scotland – The Challenge” (Scottish Executive, 2003i). This was followed by “Delivering a Healthy Scotland – Meeting the Challenge” (Scottish Executive, 2006k). These identified the need for joint action, and the focus on partnership is also supported in the “Joint Future” policy and process, relating to joint working between local authorities and the NHS in community care.

2.86 There has been a long-term shift in health and social care policy towards supporting people to remain in their own homes. This is part of the government’s objectives for modernising social services (Inclusion Scotland, 2005) and is reflected in a number of recent developments and reports. The modernising government and modernising social services agendas seek to develop services which are more focused on the needs of individual users, and this principle is evident in the recent “Changing Lives: Report of the 21st Century Social Work Review” (Scottish Executive, 2006b). This emphasised close working between service users and professionals, giving users a much greater role in how services are designed and delivered. There is a clear focus upon early intervention, self-determination, participation, support for self care and an holistic approach to provision, with a number of recommendations reflecting this.

2.87 There is also an Equality and Diversity Strategy in the Scottish Executive Health Department, within which a strategic partnership initiative “Fair for All – Disability” has been developed by the Department, NHS Scotland and the DRC. The project aims to encourage

healthcare providers to promote the rights, independence, choice and inclusion of disabled people, through the provision by NHS Scotland of guidance and support to staff. A Sensory Impairment Action Plan has also been developed, to improve access for sensory impaired people to community care services.

2.88 There are a wide range of local strategies and planning processes involving health and social work services (and others) which impact on disabled people. While some of these strategies are wide-ranging (for example, dealing with residential care or occupational therapy services) some are more specific to a single issue or group of disabled people.

2.89 There have also been changes to practice. For example, there have been changes to the process of assessment for community care services, with a “single shared assessment” process in place, through which a designated lead professional co-ordinates the process on behalf of all services. There were also some examples of joint approaches to other aspects of provision from respondents to this research, and although the CHPs are at an early stage, it is envisaged that their establishment, and the provision of devolved resources and decision making to frontline staff, will allow those working in health and social care to take a more holistic view of provision.

2.90 Other developments which have impacted either separately or jointly on health and community care for disabled people include:

- An independent review of NHS wheelchair services in Scotland, completed in 2006 (Scottish Executive, 2006m).
- A review of the needs of unpaid carers completed in 2006 (Scottish Executive, 2006n).
- A scoping study on the needs of, and services to younger disabled people (Scottish Executive, 2006o).
- A best practice guide for GPs to ensure that surgeries meet the needs of patients with a visual impairment, developed by the Guide Dogs for the Blind Association working with NHS (Guide Dogs for the Blind Association, 2005).
- Examples of local target-driven approaches to aspects of community care or, in one example, an annual target for maintaining the number of people being supported to live independently.

Direct Payments and Independent Living Fund Grants

2.91 A major initiative with the potential to impact upon independent living is the development of Direct Payments. The NCIL (2006) noted that Direct Payments have changed the way in which some disabled people receive community care services. As well as accessing personal support through the services described above, there is now the option of purchasing this on an individual basis. While there have always been private support providers, Direct Payments and Independent Living Fund grants empower people to purchase their own services.

2.92 Since April 1997, when the Community Care (Direct Payments) Act 1996 came into force, Direct Payments have been available to disabled people aged 18-64. This gave local authorities discretion to provide them. This was extended later to include disabled people aged 16 and 17, and parents of disabled children, as well as people aged 65 or over assessed as needing community care services as a result of infirmity or old age. Since the implementation in 2003 of the Community Care and Health (Scotland) Act 2002, local authorities have had a duty to offer Direct Payments in place of providing services to all eligible disabled people.

2.93 The Scottish Executive has also provided guidance on Direct Payments. New draft guidance (Scottish Executive, 2006i) was issued in August 2006 with a consultation period to December 2006. Once approved, this will replace current guidance, last updated in 2003. Individual local authorities have developed assessment criteria in line with Scottish Executive guidance.

2.94 Direct Payments can be used to purchase any kind of community care support except long term residential care. This also includes housing support services (such as, for example, those provided through supported accommodation, sheltered housing, homelessness services etc.) and equipment and temporary adaptations. The current Adult Support and Protection (Scotland) Bill (if passed) will make some changes to Direct Payments provisions, allowing local authorities to be more flexible in individualised packages.

2.95 A total of 1829 Direct Payments were in place in Scotland in 2005/2006, with a contract value of £17.9m. The average Direct Payment is around £10,000 per annum, but the number and proportion of Direct Payments, and their average value, varies widely between local authorities (Scottish Executive, 2006j). There is also significant variation

by client group, with more than half of all payments (52%) being to those with physical impairments, 23% to those with learning difficulties and only 3% to those with mental health problems.¹⁴ Overall, the number of Direct Payments is rising, albeit from a very slow start.

2.96 Support is being provided to the Scottish Consortium of Direct Payment Support Organisations, particularly for the development of peer support and to provide a voice for member organisations. Direct funding has been provided to a range of organisations working with groups where take up has been low, and some targeted investment has been made in training and support to be delivered by CILs. Additionally, the Scottish Personal Assistant Employers' Network is being provided with support, and some targeted training has developed. The 2006 Spending Review noted that Direct Payments needed additional funding for start up costs (Riddell et al, 2006b) and the recognition of this was seen to be significant.

2.97 Some local authorities in this research provided detailed information about their approach to Direct Payments (in some cases, suggesting that they had a very positive approach to this). Some also provided evidence of the provision of information about their schemes.

2.98 There are many accounts of the benefits of Direct Payments for disabled people, in increasing their choice, control and participation, and in improving their quality of life, emotional, physical and social health. Discussion group and individual participants described Direct Payments as "liberating", as well as identifying their impact on their confidence, ambitions and independence. There is also evidence that they are cost-effective, and can represent a significant saving to service providers and the Exchequer.

2.99 As well as Direct Payments, two "Independent Living Funds" provide financial support to enable some disabled people in the UK who require more help than their local authority can provide, to live in the community. The Independent Living (Extension) Fund administers payments to clients of the original ILF (and is closed to new applicants). The Independent Living (1993) Fund is open to applications from throughout the UK from severely disabled people who meet the eligibility criteria. The Fund works in partnership with local authority social work departments, and can provide support to those who receive a minimum level of support from their social work department (either as a service or

¹⁴ The balance is largely accounted for by those aged over 65.

as a Direct Payment) and who meet other criteria. Those who receive ILF funding can also use this to buy personal care in the community.

2.100 As well as covering provision by statutory services, Direct Payments and Independent Living Fund grants can be used by disabled people to employ their own support workers who can help with the provision of personal support. Some respondents identified the benefits of having such staff, particularly in terms of the ways that this enabled them to participate in their communities. For example:

“Now ... I can do things and go places when I want to and not when family and friends can fit me in!”

2.101 In England, the provision of choice and control has been extended beyond Direct Payments to a wider commitment to “individual budgets”, building upon other mechanisms for “self-directed support”. This was a recommendation of the PMSU report (2005) and a number of pilots are under way, where individuals are given a clear cash sum, or a notional amount to use on their care or support package, with a variety of funding or support streams coming together¹⁵. The funding can be taken as a Direct Payment, as services, or as a mix of both.

2.102 Direct Payments Scotland (2003) identified an overall commitment by the government to promoting independent living through Direct Payments. Riddell et al (2006a; 2006b) however, suggest that it is not clear how far this might potentially involve individualised budgets. The results of the pilots in England are expected in 2008, and the outcome will clearly be relevant to developments in Scotland in the future.

OPPORTUNITIES FOR ECONOMIC AND SOCIAL PARTICIPATION

2.103 The fourth key strand of independent living is the need to ensure that disabled people who wish to do so can access work, leisure and other social and civic opportunities and again there have been some changes.

¹⁵ These include: social services; integrated Community Equipment Services; Access to Work; the Independent Living Fund; the Disabled Facilities Grant; and Supporting People (ODI, 2006).

Employment

2.104 Employment policy and legislation remains reserved to Westminster, although the Scottish Parliament can highlight particular issues to the UK government and can ask for these to be taken into account. There are a wide range of agencies involved in the provision of employment opportunities, some of which are controlled by the UK Parliament (such as Jobcentre Plus) while some are local (such as Scottish Enterprise and the Business Gateway, as well as local authorities).

2.105 In terms of legislation, the DDA (1995) has implications for employment rights, with employers required to make 'reasonable adjustments' and disabled people having the right to challenge discrimination. Public sector employers, and employers in other sectors carrying out public functions, are also required (under the DDA, 2005) to promote positive attitudes to disabled people. A further major development has been the publication of the Green Paper "A New Deal for Welfare: Empowering People to Work" (Department for Work and Pensions, 2006a), one of the purposes of which is to ensure that people who are able to enter work have the opportunity to do so.

2.106 Government schemes provide support with employment issues and are made available through Jobcentre Plus in Scotland. Examples include:

- A pilot "Pathways to Work" initiative in a number of areas in Scotland, England and Wales, designed to improve opportunities for people on Incapacity Benefit and to assist people to return to work. Amongst the proposals in "A New Deal for Welfare" are that the existing pilots should be rolled out nationwide by 2008.
- A "New Deal for Disabled People" which is an employment programme for people who claim benefits relating to incapacity, providing a national network of "job brokers" to assist disabled people into employment.
- A national "Access to Work" scheme to assist disabled people in paid employment throughout the UK, by addressing practical obstacles in their working environment. The DWP is reviewing Access to Work, and the ODI (2006) noted that the review aims to promote greater inclusion and equality.
- WORKSTEP, an employment programme which provides support to employers and employees (and other practical help).

2.107 In July 2006, Edinburgh, Glasgow and Dundee were named as Pathfinder areas for a new “Cities Strategy”, promoted by the DWP, which is aimed at developing local partnerships to tackle social and economic inclusion, including low levels of economic participation by disabled people (mentioned as an issue by two of the three Scottish cities). The work is still at an early stage.

2.108 There are staff in local job centres with a remit to help disabled people to enter and sustain employment. Local authorities and some voluntary organisations are involved in the provision of supported employment schemes, and there are a range of other such schemes around Scotland involving other organisations. One provided examples to this study of a wide range of men and women who had been supported to move into open employment (in all cases on a significantly higher income than when solely reliant on benefits). CILs also provide work-based training and placement, which can be a route to other employment (Gillinson et al, 2005).

2.109 The Scottish Executive has also taken a proactive approach to some aspects of employment. “A Smart Successful Scotland” was published in 2004, providing strategic direction to the enterprise networks, as well as an enterprise strategy for Scotland. One of the cross-cutting themes within this was to *“close the gap in opportunities and quality of life between different groups and areas within Scotland, strengthen communities and promote equality of opportunity”*. The need to work with equality bodies and to ensure that businesses are aware of their responsibilities, and to eliminate discrimination and promote the business benefits of equality are stressed. Additionally, as noted previously, one of the objectives in “Closing the Opportunity Gap” launched in 2004 included:

“To increase the chances of sustained employment for vulnerable and disadvantaged groups - in order to lift them permanently out of poverty”.

2.110 In 2006, the Scottish Executive launched an employability framework entitled “Workforce Plus: An Employability Framework for Scotland” (Scottish Executive, 2006d). This identifies how the Scottish Executive will support those furthest from the labour market to enter work. It is being funded through “Closing the Opportunity Gap” resources, and has been welcomed by the Scottish Parliament (The Scottish Parliament, 2006a). Its proposals include the establishment of

local employment partnerships to deliver appropriate services, and other national and local actions to help disadvantaged people into employment. There will be a National Workforce Plus partnership to provide overall support. A reduced role is envisaged for Jobcentre Plus in the provision of employment services to disabled people, and a greater role for private and voluntary sector organisations.

2.111 Amongst other relevant developments are:

- “Working for a Change? The Same as You?” (Scottish Executive, 2003d), the report of a short life working group which made recommendations relating to the employment of people with learning difficulties which are now being taken forward.
- “Healthy Working Lives: A Plan for Action” which aims to improve the provision of occupational health in Scotland (Scottish Executive, 2005d).
- SUSE’s “Blueprint for Supported Employment” in Scotland, which defines the roles and responsibilities of various organisations (Scottish Executive, 2006a).
- The Volunteering Strategy (Scottish Executive, 2004b) which links to the development of appropriate experience and skills for employment, and has a particular focus on disabled people. In 2005, VDS published research into the experiences of disabled people in volunteering (Reilly, 2005) and, since then has worked with a variety of organisations (including the DRC and SDEF) to promote volunteering, and good practice in the management of disabled volunteers.

Education and training

2.112 Education and training are largely devolved policy areas. Schools in Scotland are, for the most part, controlled by local authorities. Colleges and universities are independent, although in receipt of significant public funding, and subject to Scottish Executive and UK government policy and legislation. There are a small number of what have been referred to as “special schools” in Scotland, funded by the Scottish Executive and local authorities (some of which are independent charities), for pupils with high levels of additional support needs.

2.113 One of the national priorities in school education in Scotland (which were approved by the Scottish Parliament), relates to “inclusion and equality”, and there is a range of relevant educational legislation, including:

- The Standards in Scotland's Schools etc. Act, 2000, which stated that education authorities should, except in 'exceptional circumstances', provide education for children of school age in a mainstream school, rather than in a special school.
- The Special Educational Needs and Disability Act 2001 (an amendment to the Disability Discrimination Act 1995) which made discrimination against disabled students in the provision of education, training and other related services unlawful.
- The Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002 which gave educational providers additional duties to develop accessibility strategies for the built environment and the curriculum; as well as to improve communication for disabled pupils.
- The Education (Additional Support for Learning) (Scotland) Act 2004 which addressed concerns with the assessment and recording system for children with additional support needs, ensuring that those with the most complex needs would have a co-ordinated plan to support their education. It also required authorities to make adequate and efficient provision for children and young people with additional needs, and made provision for planning transitions and providing support at these times.
- The Disability Equality Duty, which requires that providers do not to discriminate in further and higher education.

2.114 Alongside the legislation, there has been an increasing move to educate disabled children and young people in mainstream schools (Scottish Council Foundation, 2005) and DEMOS (2006) suggesting a general acceptance of the concept of inclusion. A forthcoming report (University of Birmingham) notes that many schools have made considerable efforts to enable children and young people to access both the school environment and curriculum and to meet their individual needs, and the role of specialist provision has also been recognised (HMIE, 2002). It has been suggested that the reclassification of "special needs" as "additional support needs" will contribute to reducing the stigma faced by disabled people in education (DRC, 2006c).

2.115 There are also a number of strategic documents which are relevant to independent living, and the Scottish Executive is clearly committed to promoting participation in education and learning (Scottish Council Foundation, 2005). These include:

- A report entitled “The Same as You? A Review of Services for People with Learning Disabilities” (Scottish Executive, 2000b), which included recommendations about improving access to educational opportunities.
- A lifelong learning strategy entitled “Life Through Learning; Learning Through Life” (Scottish Executive, 2003c) which focuses mainly upon post-compulsory education, training and learning, with five goals which are clearly relevant to independent living.
- “Partnership Matters: A Guide to Local Authorities, NHS Boards and Voluntary Organisations in Supporting Students with Additional Needs in Further Education” (Scottish Executive, 2005b). This has since been updated, and will be updated again in 2007.
- “Lifelong Partners: Scotland’s Schools and Colleges Building the Foundations of a Lifelong Learning Society - A Strategy for Partnership” (Scottish Executive, 2005c).
- “More Choices, More Chances: A Strategy to Reduce the Proportion of Young People not in Education, Employment or Training in Scotland” (Scottish Executive, 2006e). This strategy aims to reduce the proportion of 16-19 year olds who are “NEET” and recognises the importance of key workers to provide a one to one service to young people with additional support needs.

2.116 Other developments include: a range of initiatives being trialled through the “New Deal for Skills” which is aimed at improving learning and training for people who receive benefits and have low skills; the publication in 2002 of a toolkit by the Scottish Funding Council to ensure that providers comply with their DDA responsibilities, as well as a training and development programme; and the establishment in 2006 by the Scottish Further and Higher Education Funding Council of “Equality Forward”, a body to support institutions in implementing their duties.

2.117 In terms of transitional periods, the Scottish Council Foundation (2005) identified that some multi-agency projects also provide key worker support at these stages for young people in Scotland who have additional support needs. The Scottish Executive, in their response to the Disability Working Group report (Scottish Executive, 2006c) recognised the importance of transition points and stated that action was being taken through a range of initiatives. Some local authorities indicated that they had put services in place to help effect transition (for

example, “15-24 East Lothian” which works with young people and their families, addressing employment and other general barriers).

2.118 There are also examples of other relevant current work, and the Scottish Parliament Disability Inquiry report (The Scottish Parliament, 2006a) noted that the funding system for further and higher education in Scotland was being reviewed. The ODI (2006) noted that the National Bureau for Students with Disabilities has been commissioned to develop materials to help some of those advising disabled people. The Scottish Executive has established a “Disabled Students’ Stakeholder Group” which is considering support to disabled learners in further and higher education (Scottish Executive, 2006c).

2.119 The Scottish Parliament Disability Inquiry report (The Scottish Parliament, 2006a) identified a “Teachability Project” in Scotland which supports staff in universities to improve the accessibility of what they offer. This has been rolled out to a number of institutions. Work done by Skill Scotland suggests that there can be value in demonstrating the potential of independent living to disabled children to allow them to become familiar with the concepts before approaching services as an adult. As in other policy areas, there has also been a range of local work, and it is clear that, as in other areas of policy there have been developments in education and training which are relevant to independent living.

Leisure, social and public life

2.120 Virtually all aspects of policy development and regulation in leisure, social and public life are devolved to the Scottish Parliament and, as with most other policy areas, the main aspect which is reserved relates to the provisions of the DDA. Leisure and social activities are provided by a large range of organisations, including the private sector, local authorities and voluntary organisations. Many bodies have a direct interest in regulation, promotion and accreditation of provision, including national and local arts and sports bodies, and, for example, Visit Scotland. Volunteer Development Scotland (VDS) also has a significant role (as most leisure and social organisations rely heavily on volunteers), as do transport providers.

2.121 Leisure and cultural services (including the arts) are covered by the general provisions of Part III of the DDA, which has had a significant impact on the visitor attraction and leisure and accommodation sectors. Strategies and policy documents have also been developed, including:

- “Sport 21 2003-2007 Shaping Scotland’s Future” (Scottish Executive, 2003f) which set out a range of ways that sport for disabled people could be developed, both in the context of mainstream and specialist sports settings and identified a significant investment in the accessibility of sports facilities across Scotland.
- “Supporting Arts and Disability” (Scottish Arts Council, 2006), which set out policies for disabled artists (and indirectly for disabled people as consumers of the arts) and identified an ongoing commitment to support disabled artists, and to develop venues and means of delivering the arts (described as “inclusive access”) within the wider context of the DDA.

2.122 There have also been other developments, and the range of leisure and social activities available to disabled people has expanded greatly in the last 10 – 20 years, partly as a result of developments to physical access and communications and, as DEMOS (2006) identified, partly as a result of technological developments which increasingly enable disabled people to take part in some leisure activities. There has also been an expansion in the availability of information about leisure and social opportunities for disabled people, largely through the internet.

2.123 It is clear from responses to this research by local authorities that a great deal has been done to facilitate access to leisure by disabled people. For example, one indicated that it provides accessible changing facilities at all leisure centres, and has installed equipment to make all swimming pools accessible, portable hoists to allow lifting of wheelchair users onto equipment, low level counters, induction loops at all information points, and powered doors.

2.124 The UPDATE service, working in partnership with CILs, provides a CD-ROM based guide to accessible holidays in Scotland, dealing not only with access issues, but also access to support. Visit Scotland also provides access to the searchable national database of RADAR accessible toilets. It has also published “Accessible Scotland”, a paper-based guide to accessible facilities, with the intention to extend this to cover on-line services in 2007 (with this information already being available via Tourist Information Centres and via telephone helpline services). Visit Scotland identifies facilities which are accessible to various “categories” of disabled people (broadly classified by the nature of their impairment) as part of its quality assurance scheme. This

information is published as part of the summaries available on inspected properties.

2.125 In terms of public appointments, RHA carried out a review of diversity issues in 2003. A Strategy for Equal Opportunities in the Public Appointments Process will be introduced in summer 2007 by the Commissioner for Public Appointments in Scotland (Scottish Executive, 2006c), again providing an opportunity to develop work to promote independent living.

Income

2.126 Within the overall need for an appropriate income, there are two strands: income and poverty; and benefits. There are also links to employment, as this (or the lack of it), can have an impact on the level of income available to disabled people, as well as on the levels of costs incurred by disabled people, including community care charges.

2.127 The welfare benefits system is reserved to Westminster, although some aspects of its implementation can change at a local level. There are a number of relevant benefits for disabled people, including: those providing for extra costs (e.g. Disability Living Allowance and Attendance Allowance); benefits providing earnings replacement (e.g. Jobseeker's Allowance; Incapacity Benefit); means-tested benefits and tax credits (e.g. Income Support; Working Tax Credit; Housing Benefit; Council Tax Benefit); and compensatory benefits (e.g. War Disablement Pension; Industrial Injuries Disability Benefit) (PMSU, 2005).

2.128 There have been some recent major developments to the welfare system in the UK, particularly with the Welfare Reform Green Paper "A New Deal for Welfare: Empowering People to Work" (Department for Work and Pensions, 2006a). The Green Paper proposed major changes to Incapacity Benefit, recognising a number of difficulties with the current situation and proposing a range of changes. It is envisaged that there will be a new "Employment and Support Allowance" to support people who are unable to work, and offer incentives for people to work (with most new claimants being required to participate in work-related activities, or have a reduction in their benefit levels).

2.129 The PMSU report (2005) noted a considerable rise in government spending on disability-related benefits in the last two decades. The Scottish Council Foundation (2005) also noted that there are more people who now claim benefit because of incapacity than unemployment

and lone parenthood together. Research for the ODI by SQW (2007) suggests that the early experience of investments to support disabled people to remain in employment is to both reduce the level of reliance on benefits, and add to potential tax revenue.

2.130 The Office for Disability Issues (2006) noted that it is also proposed to make changes to the Personal Capability Assessments process, which will involve assessing capacity for work instead of simply entitlement to benefits. The same report also outlined changes relating to rules about working and benefits.

2.131 The Scottish Executive has an expressed commitment to social justice / social inclusion, and the need to focus core public services on disadvantaged areas and to support social capital in communities has been recognised in “Better Communities in Scotland: Closing the Gap” (Scottish Executive, 2002b). Within this, the disadvantaged position of disabled people has also been identified.

2.132 The Scottish Executive (and UK government departments) have also put in place a range of initiatives which recognise that disabled people face additional costs. Some of these have been mentioned earlier, and they include concessionary fares, free personal care and support for housing improvements.

FUNDING AND RESOURCES

2.133 The final broad area which impacts on independent living is the provision of funding and resources to support this. At an individual level, the main means of funding independent living in Scotland are through community care assessments and through people making application to the Independent Living Fund (Inclusion Scotland, 2005). In terms of services and strategic developments relevant to independent living, however, there is a complex range of funding sources. Some are national UK sources (such as, for example, Access to Work, Pathways, and the New Deal for Disabled People). There is also a great deal of relevant Scottish Executive funding, including mainstream health, residential care, social housing and community care funding, as well as initiative-based funding such as Supporting People, Closing the Opportunity Gap, and direct funding for some transport and community care services.

2.134 Control of Scottish Executive funding rests with individual departments, although the Equality Unit takes a cross-departmental view

of spending on issues relevant to disabled people. Little of this is actually distributed by the Scottish Executive, but it is used by agencies (such as Scottish Enterprise, Communities Scotland or Visit Scotland), local authorities and NHS bodies, or the voluntary sector (including specialist housing providers).

2.135 The processes involved in the distribution of this funding are complex. Increasingly, public bodies are receiving funding from the Scottish Executive which they then use to purchase services from third parties (for example, through the Supporting People strand). While this is generally from the voluntary or private sectors, it can also be from other parts of individual local authorities. Direct Payments is yet more complex, where the Scottish Executive provides money to local authorities to provide services, who then distribute it to individual disabled people to purchase support.

2.136 The Scottish Executive is also a significant provider of indirect support to disabled people through funding for voluntary organisations (e.g. to support Direct Payments). In many cases, this is distributed on the basis of contracts or service level agreements. At a wider level, charitable trusts are significant funders of services to disabled people and, in virtually all cases (with the exception of some arts and sports grants) this is indirect, being provided to voluntary organisations (or partnerships between the voluntary and public sectors). Most voluntary organisations working in the broad area of independent living will be funded using a complex package of public, trust and legacy income, some of which will be tied to output-related contracts.

2.137 There are a number of layers of scrutiny for these resources, including ultimately the Scottish Parliament, but also Audit Scotland (which has undertaken some work on disability issues) and the DRC. At a local level, scrutiny tends to be via elected or representative bodies. There is also a wide range of relevant inspection and registration regimes, the most obvious being the Care Commission and Communities Scotland, but there are many others (including, for example, Visit Scotland).

OVERVIEW

2.138 It is clear that there have been many recent changes and developments which offer opportunities for independent living. Against this background, however, there remain many areas of inequality and discrimination in disabled people's lives. It is also essential to identify

these, and some of the main barriers which impact upon opportunities for independent living are highlighted in the following section.

SECTION 3: GAPS AND BARRIERS

3.1 Alongside the examination of legislative, policy and practice developments, it is important to identify the current position of disabled people and the reality of their lives and experiences. Despite the expressed intention of some of the legislative and policy developments, there remain many barriers to independent living and equality. Independent living was identified by some stakeholders in the Scottish Parliament's review of equalities work (RHA, 2006a) as an area in which progress had been more limited than anticipated. Work for the ODI undertaken by SQW (2007) suggests that some organisations (such as some local authorities and NHS bodies) remain reluctant to embrace the principles of independent living, and the report argues that this is unsustainable both from a rights and economic perspective.

3.2 Overall, disabled people continue to experience poorer outcomes in many aspects of their lives than non-disabled people. DEMOS (2006) identified that the policies and practices of a wide range of organisations still result in disabled people being treated less favourably. Many disabled people continue to lack access to the choice, control and freedom which are necessary for independent living, and which are enjoyed by non-disabled people. While this section clearly cannot comprise a comprehensive account of all of the constraints to independent living, it identifies some of the key issues.

THE POLITICAL, SOCIAL AND SERVICE STRUCTURE

3.3 Despite progress, there remain aspects of the political, social and service structure in Scotland which militate against independent living.

The decision making structure

3.4 In terms of the decision making structure, the lack of an explicit structure for the consideration of independent living issues has been highlighted. The report of the Scottish Parliament Disability Inquiry (The Scottish Parliament, 2006a) noted that there is not yet an Independent Living Task Force in Scotland. There is also often a lack of clear structure in other organisations, at a national and local level, through which equality, disability and independent living issues can be considered. There is also seen to be an overall lack of "joined up thinking" and communication about independent living.

3.5 There are also concerns that, even where there is a structure for equalities work, not all parts of organisations share the same level of commitment to this (RHA, 2006a), nor to the principles which impact upon independent living, with variation in the level of understanding of key concepts such as the social model of disability. The Scottish Parliament's Disability Inquiry report (The Scottish Parliament, 2006a) identified concerns about the level of shared commitment and the pace of mainstreaming. A survey by the DRC published in February 2007¹⁶ identified that 45 public bodies had, by that time (3 months after the deadline) failed to produce a Disability Equality Scheme. The public bodies concerned included a local authority, 3 colleges, 4 grant-maintained schools, 30 licensing boards, 3 valuation boards, 3 national arts and leisure organisations and one police board. The DRC also expressed concern that, among the colleges which had produced Schemes, around two thirds had failed to adequately involve disabled people in their preparation.

3.6 There can also be limited use of opportunities within existing structures to influence developments. The ODI (2006) noted that there can be a lack of leadership for taking the equalities agenda forward, or a lack of an overall strategic approach (ODI, 2006). It has also been suggested that independent living lacks a "champion" in a high profile role who could drive the work forward, and that there can be some reluctance to adopt the concept. It has also been suggested that the provision of guidance on legislation and policy does not always promote independent living, nor do the processes of standard setting and scrutiny of provision.

3.7 Concerns have also been expressed about the level of input to reserved issues from Scotland (RHA, 2006a). Some of the problems which have been suggested include that there can be: limited influence on Westminster policy from Scotland; a lack of communication between Westminster and the Scottish Executive / Parliament; confusion about devolved issues and "grey areas"; and sensitivity and lack of clarity about the level of input to reserved issues which is possible. Some disappointment was also expressed in the Disability Inquiry report (The Scottish Parliament, 2006a) that the Scottish Executive had not been more proactive in relation to the recommendations which were made in the PMSU report (2005).

¹⁶ http://www.drc.org.uk/about_us/drc_scotland/news/disability_equality_duty_enfor.aspx

3.8 There is some concern about the impact of the CEHR on individual equalities strands, including disability, and uncertainty about: how organisations will interact with the CEHR (RHA, 2006a); arrangements for equalities work in Scotland (Inclusion Scotland, 2005); and whether there will be sufficient resources to support the work (RHA, 2006a).

Policy and legislation

3.9 There are also problems with some policy and legislation, which do not reflect and support a commitment to independent living. Some policy and legislation uses language and definitions which do not reflect the principles of independent living. There can be a lack of clarity about the use of terms such as “equality”, “disability”, “independent living” and the “social model”, and the use of inappropriate and offensive terminology. An example often cited is the National Assistance Act 1948, which excludes many people who need support (DRC, 2006e). Some legislation and policy is still based on language relating to “vulnerability”, “risk avoidance” and “incapacity” or “dependency” (DRC, 2006e; Stirling, 2006). A focus on these issues can serve to create dependency rather than enabling participation and independent living (PMSU, 2005).

3.10 Some policy and legislation is still based upon the medical model of disability. For example, concerns have been raised that the definition of disability in the DDA is based upon this, having a negative impact upon its implementation (DRC, via internet). At a local level, a Disability Equality Scheme provided by an NHS Board to this research defined “disability” purely in terms of the medical model (supported by an annex setting out further definitions from the DDA, 1995).

3.11 It has also been suggested that the practical effects of some legislation may be to undermine, rather than encourage independent living. For example, it has been suggested that the Adult Support and Protection (Scotland) Bill is “disablist” and poses a threat to achieving independent living (Inclusion Scotland, 2007). Issues have also been raised with aspects of mental health and other legislation, indicating that, if its impact upon independent living is not explored, the consequences can be problematic. The DRC, supported by work undertaken by SQW (2007) also suggests that new and existing policy fails to take account of the potential economic benefits of independent living, although it is argued that it can bring significant economic benefits in the medium and long term. Impact Assessment is not yet carried out consistently across policy and legislation, and considerable further work remains to be done.

3.12 There can also be contradictions in policy and legislation, fragmented approaches to policy (PMSU, 2005), divisions between relevant areas and the benefits of one piece of legislation diluted by the provisions of another. Stirling (2006) suggests that there is a concern that the sheer volume of new equalities legislation may dilute the specific emphasis on disability issues. The DRC (2006e) note that “*existing law is a mess*”, and that community care law is “*a hotchpotch of conflicting statutes, which have been enacted over a period of 50 years*”.

3.13 Additionally, some policy, legislation and strategic documents simply do not consider issues for disabled people, and the Scottish Parliament’s Disability Inquiry (2006a), identified that many of the Scottish Executive’s key publications did not reflect these issues, even though there was a requirement, or opportunity to do so. Similarly, it has been noted that high level strategic plans in some local authorities do not address relevant issues in sufficient detail, if at all (Stirling, 2006) and commitments which are made do not always lead to the development of action plans (DRC, 2006a) or translation into practice. The PMSU report (2005) noted that there can be a particular lack of recognition of enabling access by disabled people in policies and services which do not specifically target disabled people, despite the fact that many services are relevant to enabling independent living.

3.14 Similarly, planning processes are not always required to take account of these issues, and the Scottish Council Foundation (2005), for example, noted that the community planning process in Scotland does not have any specific provisions relating to planning for disabled people, nor priority for this as a key policy area.

3.15 There is also a lack of an evidence base to inform policy (DEMOS, 2006; The Scottish Parliament, 2006a), including a lack of information about the experiences of disabled people. It became clear in discussion groups that disabled people are not necessarily consulted in the development of new policies and services, potentially making it more likely that there is no recognition of their needs (see para 18 below).

3.16 Gillinson et al (2005) suggested that the adoption of a rights-based, independent living approach can be challenging to policy makers and service providers who have traditionally adopted a welfare-based approach. SQW (2007) suggest that the loss of control of budgets can also be challenging to service providers. Disabled people have very few legislative rights to services (DRC, 2006e) which would ensure that they

would obtain the assistance required for independent living. As Parker (2004) notes, disabled people do not have positive rights to choose where or with whom they live; have only limited legal entitlement to advocacy; have no right to communication support or “portable support” on moving. There can also be difficulties in enforcing existing legislative entitlements, and even where there is a commitment to addressing issues, this may not be translated to action, or legislation and policy may be “flouted” (DRC, 2006b).

3.17 Zarb (2006) identified that the Human Rights Act has not been used on many occasions for cases relating specifically to independent living, although Parker (2004) identified many ways in which failure to implement independent living in a consistent and effective way may breach the Act. Parker notes, for example, that the way in which support is delivered could constitute an infringement of specific Articles (citing the decision to remove an individual’s right to live independently by placing them in institutional care). Other examples include the use of budgetary prioritisation, rather than need, to decide the level of support for an individual disabled person¹⁷. Parker also argues that a failure to provide access to Direct Payments could be open to challenge as a breach of Article 8, in relation to the right to a family and private life.

Inclusion and empowerment

3.18 As noted above, it remains the case that the views of disabled people are often not sought on issues which affect them (Scottish Executive, 2006a). The PMSU report (2005) identified that disability groups have not been well-represented in the development of policy, and this theme was reiterated by respondents to this research. It was also suggested that disabled people may find it difficult to have their views made known to Parliament about legislation under consideration.

3.19 At a structural level, there are not always clear mechanisms at a national or local level for involvement of disabled people. A lack of capacity amongst organisations led by disabled people (RHA, 2006a), can also limit participation. They may be under-resourced to provide the input required, and this can be compounded by the high volume of relevant legislation, policy and practice. In some cases, organisations have to combine a service delivery and policy development role, with no funding for the latter. The move towards service level agreements and contracts can also impact on this, as policy development is not often

¹⁷ This has already been the subject of successful court action in England.

funded through these means. There can also be a lack of resources to enable individuals to take part in consultation, and all of these difficulties can undermine the representation of disabled people.

3.20 There can also be a lack of willingness to involve disabled people, and some staff may not recognise their skills and expertise. Where involvement does take place, there can be problems with the ways in which it is undertaken, and a recent review of equalities work (RHA, 2006a) identified a range of perceived problems with the nature and methods of consultation and engagement with equalities groups. Two group discussions noted that little regard is often given to disabled people in arranging venues, and concern was expressed that the “necessary adjustments” made can be demeaning. Additionally, even where prior notice is given, arrangements may not have been made.

3.21 There are also sometimes differences between user-led organisations and policy makers, organisations of and for disabled people, and organisations for people with different impairments about the way forward (PMSU, 2005). There are also concerns about “tokenistic” involvement and a lack of involvement throughout processes.

Information, advice and advocacy

3.22 There are gaps in the provision of information, advice and advocacy to enable disabled people to recognise their rights and exercise their choices. Generally, provision varies across Scotland and there is a lack of an overall network of user-led organisations to support independent living (DRC, 2006a). There are only two CILs in Scotland, and they face resource constraints and high demand, which can lead to waiting lists for support.

3.23 There are also gaps in particular forms of support, which include:

- User-led, independent support, as some organisations have become more involved in direct service provision than advocacy, and other organisations have become involved in support provision.
- Support services to enable the use of Direct Payments, and intensive support for some marginalised groups (Luckhurst, 2005) with some “precarious” funding.
- Support to address emotional needs at times of transition, and access to peer counselling, building on a model of peer support. Disabled people face barriers to accessing other

counselling services and many counsellors lack experience of working with disabled people.

3.24 Where information, advice and advocacy are available, there are other constraints. For example, a range of organisations can be involved, with individual disabled people having to approach a number of these for different aspects of information (ODI, 2006). There can also be a lack of information sharing between organisations which are supporting independent living (Gillinson et al, 2006). Some of the more generic rights-based organisations do not always have the expertise required, and advice may not always be appropriate. For example, one respondent suggested that advice would be unlikely to be impartial from a service provider if the organisation was under financial pressure.

3.25 Disabled people are often unaware of the existence of support, or cannot access it (ODI, 2006; Social Exclusion Unit, 2005). It may not be provided at a suitable time, or at the appropriate stage, and a recent report (SQW, 2007) suggests that the lack of timely provision can be a barrier to the take-up of services. It also suggests that people may not be made aware of their options relating to independent living until they are in crisis. These situations are then often referred to as CILs, as services have not been involved at an early enough stage.

3.26 Information is not always easy to find, or may be in the wrong formats, and inaccessible. There is limited awareness of the importance of providing information in alternative formats, particularly in the private sector (The Scottish Parliament, 2006a) and many public service internet sites remain inaccessible to many disabled people.

3.27 Where people have communication support needs, they can experience a range of inappropriate responses (Scottish Executive, 2006a) and may be ignored or insulted, as well as experiencing discrimination in access to services and employment. For example, detailed information about some aspects of employment is generally accessed via telephone. Communication needs are not always addressed (Scottish Executive, 2006a) and telephone helpline services rarely cater for people with communication impairments. There is also a shortage of BSL interpreters (The Scottish Parliament, 2006a).

Attitudes and behaviour

3.28 There is strong evidence of problems with aspects of public and staff attitudes and behaviour towards disabled people, and many

continue to experience prejudice and abuse from other members of the community, or “disablism”. The PMSU report (2005) suggested that these negative views can be a barrier to participation. It was also suggested in this research that, if the independent living agenda is successful, there may be a further “backlash” against disabled people.

3.29 There is clear evidence of negative attitudes to disabled people (conscious or unconscious), inappropriate assumptions and stereotypes, hostility to, and harassment of disabled people (RHA, 2006b; Scottish Executive, 2006a). People often define disabled people in terms of their impairments (Scottish Council Foundation, 2005) or view them as generally inferior and incapable (Gillinson et al, 2005), and there are often low expectations about what disabled people can do (PMSU, 2005). Respondents to this research provided many examples of being patronised, treated with a lack of respect and subjected to stereotypical assumptions and low expectations. There is also evidence of disabled people facing overt hostility.

3.30 The PMSU report (2005) cited a DRC study which identified that 21% of disabled people who responded had experienced harassment related to their impairment. Evidence from Scotland (DRC, 2004b) identified that 47% of disabled people in the survey had experienced hate crime because of their impairment, with the most common form of attack being verbal abuse.

3.31 There is also evidence to suggest that inappropriate assumptions and negative views can be reflected amongst service providers (Stirling, 2006), employers (PMSU, 2005) and colleagues (Scottish Council Foundation, 2005), leading to inappropriate responses. This may reflect a lack of understanding or awareness, and it has been noted that there is a general lack of understanding of “independent living” outwith those who are most closely involved in this (Gillinson et al, 2005). One of the respondents to this research identified their experience of contact with their local authority complaints system, where they found little awareness of independent living.

3.32 A lack of knowledge can also lead to staff making assumptions about people’s needs without asking them directly; to a “hierarchy” of disability where some impairments are more widely recognised than others and a lack of attention to the needs of people with hidden impairments, or those who require mobility aids on some, but not all days; and to a lack of involvement of other services which could enable an individual to get person-centred support. There can also be a lack of

sharing of good practice information (The Scottish Parliament, 2006a). Disabled people themselves can also hold negative attitudes about their own skills and abilities, as the experiences of many disabled people have traditionally been of disempowerment (Gillinson et al, 2005).

3.33 The role of the media in presenting or sustaining inappropriate attitudes has been noted, as has a lack of representation of disabled people in the mainstream media. Where disabled people are represented, this often involves emphasising “difference” (PMSU, 2005) and patronising and victim-based language is often used, particularly in relation to mental health. The overall lack of involvement of disabled people as employees in the media industry has also been highlighted (Inclusion Scotland, 2005).

3.34 There are also current gaps and limitations to disability equality training which impact on addressing attitudes. These include: different approaches and forms of provision; a lack of centralised information and register of providers; a lack of evaluation; and a lack of recognised benchmark standards (Scottish Executive, 2006a; The Scottish Parliament, 2006a).

Cross-cutting service issues

3.35 There are also many cross-cutting barriers in service provision which can have a negative impact on independent living. Evidence suggests that overall access to services is generally lower and poorer for disabled people than other members of the community, and a DRC survey in 2003 found that most respondents considered that not enough was done to ensure that disabled people were able to use services in the same way as other members of the community (DRC 2004c).

3.36 A complex range of services and processes are involved in promoting independent living, and current policy and practice have been implemented in a piecemeal fashion. There are also variations in practice within and between services in their commitment to, and understanding of, independent living and mainstreaming, which can lead to different responses. Services do not always have the same goals, nor work towards the same ends.

3.37 There can be different procedures for different services, with different policy, professional and service boundaries for planning services and providing support. There can be fragmented or “segmented” provision, a lack of joint working (PMSU, 2005; Gillinson et

al, 2005) and, as one respondent noted, choices can be “stifled by local bureaucracy”.

3.38 An example of the practical effect of some of these issues is the provision of equipment and adaptations, with responsibility for this in a variety of sectors and organisations. The report “Equipped for Inclusion” (Scottish Executive, 2003e), identified some of the issues, stating that:

“The current dislocation of the component parts of equipment and adaptations within a variety of sectors, organisations, departments, and professional specialisms has contributed to the inefficiencies, bureaucracy, and delay that blight the delivery of assistance to the very people who could benefit”.

3.39 Similar issues were raised by Audit Scotland (2004) and such difficulties can be applied to other aspects of provision, with a lack of an holistic approach to an individual’s requirements. Particular problems have also been identified at points of transition (e.g. school to work, further or higher education, and at the transition to adulthood), when there can be a lack of co-ordination and continuity of support.

3.40 There can also be problems with physical access to services, and the group discussions identified the reluctance of some service providers to carry out access audits, or involve disabled people in reviewing facilities. There can also be problems with availability and affordability of services. Information can be patchy or unavailable, and may not be provided in appropriate formats or ways. Many disabled people and service providers do not have a clear idea of disabled people’s rights. Some group participants identified difficulties in finding basic information about issues relevant to independent living, particularly where users were not “internet literate”. Advice and information providers also sometimes find it difficult to get information about services, and are not always told of service changes.

3.41 There can be specific access problems for some groups of disabled people (e.g. people from ethnic minorities, older people) who may be reluctant to seek support or who face other forms of discrimination. One respondent noted that there can be specific issues for people with particular impairments (e.g. dementia), who may not be diagnosed sufficiently early to be involved in decisions about their care.

3.42 Concerns have also been raised with some aspects of the means of service provision. The discussion groups suggested some movement away from designated workers towards an on-call system, where the same worker does not deal with individuals from start to finish. This was seen to lead to some level of duplication.

3.43 It has also been suggested that services may be designed and provided to suit providers, rather than disabled people, and the needs of disabled people may not be at the heart of provision. Assessments are often seen to focus upon services' rather than users' needs, and service provision can be inflexible and inaccessible. "Personalisation" is not the norm, and service users are expected to "fit" (PMSU, 2005; Gillinson et al, 2005). Participants in one group discussion noted that changes could be made to services at short notice, or without adequate consultation. Zarb (2006) identified that the lack of effective rights for disabled people means that this can still take place, and access to services can remain problematic, despite the granting of specific rights under the DDA 1995.

3.44 The group discussions suggested a concern that health and safety and "insurance" are being used to justify failure to make effective provision to disabled people. There was also a general view that cost, rather than need, was the key driver of service provision. It has also been suggested that there is little measurement (or formal inspection) of the performance of services against factors which would indicate the promotion of independent living. There can also be a lack of accountability and management, with no recognised standards for independent living.

THE ENVIRONMENT

3.45 As well as these cross-cutting issues, there are barriers relating to aspects of the built environment, transport and housing.

The built environment

3.46 The built environment, for many disabled people, is currently not accessible, and:

- DEMOS (2006) noted the small proportion of public buildings (17%) which complied with the mobility standards of the Building Regulations¹⁸.

¹⁸ in this case in London.

- The DRC (2006c) has indicated that many premises remain inaccessible, and this was also highlighted by respondents to this research.
- Access has been identified as an area in which progress has been limited since 1999 (RHA, 2006a).
- A range of studies indicate access problems (Scottish Council Foundation, 2005; Chowdhury and Worley, 2003; Capability Scotland, 2003a).

3.47 A range of factors limit access to buildings and public places, such as a lack of, or inappropriate: entrances and ramps; toilets; lifts; counters; signage; hearing loops; information; and a wide range of other issues (The Scottish Parliament, 2006a). There are many access problems in streets, including: uneven surfaces; adverse cambers; steep slopes or kerbs; a lack of marked kerbs and crossing points; hazards from inappropriately placed street furniture and bollards, and vehicular entrances (Inclusion Scotland, 2005; The Scottish Parliament, 2006a).

3.48 Many buildings were designed and constructed before current legislative provisions were in place. Aspects of their design or construction can make access difficult, and improvements may not address problems fully. Some issues, such as signage, are not currently subject to building regulations and standards (DRC, 2003a). It has been suggested that there has been a lack of funding for access improvements to key institutions, and limited adaptations to existing buildings (The Scottish Parliament, 2006a). One group discussion suggested that even new buildings may not be designed to adequately meet the needs of disabled people.

3.49 There is often limited involvement of disabled people in the design or improvement of buildings and spaces. There are variations in access panels between different areas in Scotland, and relationships between these and local authorities are not always well-developed (The Scottish Parliament, 2006a). The DRC's evidence to the Scottish Parliament's Disability Inquiry also suggested a lack of ownership by local authorities of responsibility for promoting an accessible built environment. The group discussions suggested that there can be poor understanding by staff about technology which enhances accessibility, and the DRC (2003a) note a general lack of understanding of issues affecting disabled people amongst building policy makers and practitioners, and a tendency to meet only the minimum requirements.

3.50 A lack of “joined-up thinking” can also lead to unintended consequences. One of the group discussions identified that changes to building standards relating to the acceptable incline of ramps will mean that some disabled people may lose car parking spaces, or access to parts of their property, to accommodate the longer ramp.

Transport

3.51 Disabled people do not currently have equal access to transport services. Inclusion Scotland (2005) note that many disabled people are currently unable to travel where they want to, at the time they want to. It has been found that:

- Disabled people travel less often than non-disabled people, rely more heavily on public transport because of low incomes, and face a range of difficulties.
- Fewer disabled people than non-disabled people hold a driving licence, and disabled people are less likely to have access to a private car (Scottish Council Foundation, 2005).
- The notion of “personal” transport is not currently a reality for a disabled person who does not have access to their own car.
- There can be difficulties when transferring between different modes of transport (Scottish Council Foundation, 2005) and a barrier in one strand of a journey can make an entire trip impossible.
- Assessments often do not cover transport needs (PMSU, 2005).

3.52 DEMOS (2006) whilst noting an overall positive trend in the accessibility of public transport, identified “massive barriers”, stating that:

“Be it trains, planes or automobiles disabled people still face massive challenges to getting around.”

3.53 The lack of accessible transport was identified by stakeholders as part of the Scottish Parliament’s review of equalities work (RHA, 2006a) and in a review of transport provision for the Scottish Executive Development Department carried out by RHA in 2004. The potential loss of revenue from disabled people unable to travel (whether or not these journeys are subsidised) has also been noted.

3.54 Many physical barriers were identified by respondents, including inaccessible vehicles, facilities and information. There remain many high

step buses (including all long distance coaches) in service, although provision varies between areas. Many disabled people remain unable to use “accessible” buses, and question the effectiveness of the standards used (RHA, 2004). There are many inaccessible railway stations. The group discussions identified a lack of accessible taxis outside the main cities and noted that the definition of “accessible” does not mean that all disabled people could use a taxi. One noted that there are variations in the design of vehicles, which can pose problems for some disabled people. A number provided examples of poor experiences of air travel.

3.55 The pace of improvement is slow, and it will take a considerable time for the changes being brought about by the DDA to be implemented. Many disabled people raised concerns that bus transport in Scotland is unlikely to be fully accessible much before 2020, although the relevant legislation was passed in 1995 (RHA, 2004). There is no current means of ensuring that local authorities in Scotland work to shared objectives (The Scottish Parliament, 2006a).

3.56 Parking can be impossible for disabled people who have a car, because of a lack of provision and the attitudes of others (The Scottish Parliament, 2006a). There is a high level of abuse of parking bays reserved for disabled drivers (DEMOS, 2006) and limited mechanisms to enforce this provision.

3.57 The costs of transport can be a barrier for some disabled people (Scottish Council Foundation, 2005) and it has been suggested that these are not fully reflected in levels of benefit provision (DEMOS, 2006). One respondent identified that concessionary travel is irrelevant when it is impossible to use the buses provided. It was also noted that commercial taxis are too expensive for many disabled people, except for occasional use. Anecdotal evidence was provided of operators using a two tier pricing structure, with Taxicard holders being charged a higher rate, and several participants suggested that taxicards were “limiting” and poor value. There are also a range of ways in which taxi operators can gain exemptions from carrying disabled people.

3.58 The information required for a journey is not always available, nor always provided in accessible formats (PMSU, 2005). The group discussions identified concerns about the lack of access information in national travel enquiry services. Participants gave examples of trying to get information, but being told only that a service “should” be, or “ought to be” served by a low floor bus. Additionally, the timing of services may not be appropriate to meet people’s requirements (The Scottish

Parliament, 2006a). There can be problems caused by the need to book services in advance, and there may be limited staff available to provide assistance (The Scottish Parliament, 2006a). Many disabled people are not confident that their needs will be met when travelling (RHA, 2004), and group participants suggested that being stranded on platforms was an almost inevitable occurrence for regular rail travellers.

3.59 Disabled people can also experience negative attitudes amongst transport providers and members of the public when travelling. Participants in the groups expressed concerns about the attitudes of some bus drivers to deploying ramps (echoing findings from RHA, 2004). It was also suggested that some drivers and members of the public see low floor buses as “buggy buses”, and view disabled people as a “nuisance”. Many concerns were also expressed about the attitudes of taxi drivers, and staff involved in air travel. People with mental health problems are particularly unlikely to use public transport due to a lack of confidence in the service or their safety.

3.60 There can also be specific difficulties for individual groups of disabled people. This was recognised by the Disabled Persons Transport Advisory Committee (DPTAC) in the publication of guidance for transport operators on the needs of, for example, people with visual impairments, or wheelchair users, and specific direction on attitudes is a key part of this (DPTAC, 2003).

Housing

3.61 Disabled people do not have equality and choice in housing, and:

- Disabled people are less likely to own their homes (Scottish Council Foundation, 2005) and more likely to live in the social rented sector (Communities Scotland, 2004).
- Households with a disabled person are more likely to report problems with the quality of housing and to live in older properties (DRC, 2006c).
- There has been an increase in the number of homeless households in priority need because a member of the household has a physical impairment, or a mental health problem (PMSU, 2005).
- Many disabled people live in housing which is not suitable for their needs and almost a fifth of adults with an impairment or long term illness could benefit from an adaptation or equipment (Scottish Council Foundation, 2005). The DRC in Scotland has

estimated that around 62,000 ambulant disabled people would benefit from adapted showers and bathrooms.

- Equipment and adaptations provided do not always fully address accessibility problems (Inclusion Scotland, 2005).
- 40% of disabled people in a study said their housing situation made them “unnecessarily dependent”. (DEMOS, 2006).
- Some people move to residential care, when it is not their choice, due to a lack of appropriate housing and support (PMSU, 2005).

These issues are likely to become more sharply focused over time as the numbers of older and disabled people living independently increase.

3.62 There is a general shortfall in the availability of housing suitable for disabled people (Inclusion Scotland, 2005). A great deal of the housing stock is not suitable for people with mobility or other impairments (PMSU, 2005) and the DRC in Scotland estimates that, at the current rate of progress, it would take around 50 years for the housing stock to meet the needs of the current number of wheelchair users. There are shortages of appropriate types, sizes, location and adaptability of housing in both the owner-occupied and private rented sectors (Scottish Council Foundation, 2005). The Welsh Assembly (2007) also identified that there is a lack of housing which is suitable for disabled young people to enable them to leave home and live independently.

3.63 Shelter (Doherty, 2006) identified that there is a lack of suitable temporary and permanent housing for homeless disabled people. There are also housing shortages for particular groups (including people from ethnic minority communities) and no obvious impending increases in the availability of suitable housing. For disabled people in temporary accommodation, the support packages which they received when in their own homes may be suspended. When permanent housing is available, the need for adaptations or support can lead to delays which can impact on whether an offer of accommodation (which usually needs to be considered quickly) can be taken up.

3.64 There are many problems with adaptations, such as delays (FIDN, 2007) and problems with local authority funding rules. There are also problems with: the division of responsibility, which can be confusing for service users and providers; accessing information; lengthy waiting times; lack of formal policies and procedures; and variations between areas in the nature of provision and charging (Scottish Council

Foundation, 2005). Goodridge (2004) and Audit Scotland (2004) identified a range of other problems with aspects of adaptation provision. The result can be that the adaptations either fail to meet the needs of individual disabled people, or can create additional difficulties.

3.65 The PMSU report (2005) noted that adaptations to housing can be expensive, and demand may be higher than can be met from budget allocations. There is not currently an effective way to identify the impact on other budgets of failing to provide adaptations (PMSU, 2005). There can also be a lack of resources to fund care and repair organisations in local authorities (Inclusion Scotland, 2005).

3.66 Where housing has been adapted or purpose-built and is re-let, it is often provided to people who do not need adaptations. Additionally, few local authorities keep registers to match disabled people to suitable social housing (PMSU, 2005) and there is a lack of statistical information about the housing needs of disabled people (Doherty, 2006). There is also some concern about the absence of proper projections in local housing capacity plans to deal with an increasingly older and/or disabled population.

3.67 People in residential care who want to live independently may not meet the criteria for social housing, as they are considered to have adequate housing. (PMSU, 2005). Many adult disabled people who live with their parents are also deemed to be suitably housed. Additionally, the points system does not take full account of disability issues and is often heavily reliant on medical factors (Goodridge, 2004).

3.68 There can also be problems in obtaining information about housing (Goodridge, 2004) and appropriate support. Mainstream services are not always accessible, and there is variation in specialist provision across Scotland (Goodridge, 2004). Doherty (2006) also identified a lack of co-ordination between the local provision of housing and support.

3.69 At a policy level, the issues facing disabled people are not always reflected consistently in strategic housing documents. Doherty (2006) for example, identified that the Homelessness Strategy for Glasgow did not (at that time) mention the issues faced by homeless disabled people, while the Joint Community Care Extended Partnership Arrangements 2004-2007 did identify a lack of adapted housing. The same article noted a lack of political will to address the issues and a “continuous struggle” to have these issues on the agenda.

3.70 There can also be a conflict between the objectives of different housing policies. The need to fill voids, turn stock around quickly and increase the supply of social housing can lead to providing adapted properties to those who do not need them, and removing adaptations. This reduces the availability of appropriate housing for disabled people.

3.71 The interrelationship between policy areas is also clear. Goodridge (2004) identified a range of ways in which planning policy contributed to a lack of suitable housing, including encouraging high density housing and providing restricted parking. The preference in Scotland for tenement developments has also been noted. Goodridge also identified the impact of design control issues, including: the abolition of space standards; limitations to the building regulations; lack of advice and enforcement; tensions in objectives; cost issues; and limitations to standards.

3.72 Income disadvantage can also make it difficult for disabled people to buy or privately rent property, leading to a greater reliance upon social housing (PMSU, 2005). Participants in the group discussions noted that it is very hard for a disabled person to own their own home, and cost issues have been identified in other forms of housing (Goodridge, 2004).

3.73 Participants in group discussions identified that the current re-assessment, on moving, of Direct Payments packages agreed by other authorities is a barrier to moving across local authority boundaries, with a 'risk' that the receiving authority's assessment would be unfavourable. There are also issues with the interpretation of "ordinary residence".

3.74 As with other policy areas, there also issues relating to attitudes to disabled people, including inappropriate assumptions by housing providers (Goodridge, 2004). Staff may lack training and may not recognise the needs of their disabled service users or customers.

PERSONAL SUPPORT AND SERVICES

3.75 Aspects of current policy or provision of personal support and services can also have a negative impact upon independent living.

Health and community care

3.76 Issues in health and community care services include that:

- Although there is limited information about disabled people's experiences of health and support services, disabled people face differences in health outcomes from non-disabled people (Scottish Council Foundation, 2005).
- Following a formal investigation in England and Wales (DRC, 2006f), the DRC suggested that the evidence on inequalities in health was “overwhelming”.
- Disabled people experience unequal access to health services and die earlier, often from preventable illness (DRC, 2007a).
- Some groups of disabled people face particular barriers to access to health care (DRC, 2006c).
- Most disabled people have some contact with social work services (Inclusion Scotland, 2005) but the support they require is not always made available, or is not made available at an appropriate level (e.g. equipment and other support, such as home care and personal care).
- Disabled people do not always have access to joined up and holistic provision (PMSU, 2005).
- Local authorities are increasingly providing support only to those in the most “serious” need (BBC News Jan 2007).

3.77 The number of potential recipients of support is increasing, and is projected to increase sharply over time, making these issues significant continuing concerns for the future.

3.78 There can be problems with the nature of facilities for health service provision, and one group discussion identified that hospitals (or parts of hospitals) do not always have the facilities to accommodate disabled people. There may also be inadequate staffing to provide the level of care required, and it was also suggested in a group discussion that there was inconsistency in whether or not hospitals would accept the presence of personal assistants in wards.

3.79 A number of the respondents noted that some health professionals (including GPs and nursing staff) have limited knowledge of particular impairments or issues facing disabled people, and one respondent stated that they were “sick of teaching them about me”. It has also been suggested that healthcare professionals do not take sufficient account of impairments, sometimes making assumptions about a patient without trying to speak to them (Scottish Council Foundation, 2005) and that this can impact on treatment for “common conditions”. The need for healthcare by disabled people is often seen only in terms

of their impairment (Scottish Executive, 2006a). The formal inquiry carried out by the DRC into health inequalities (DRC, 2006f) identified that people with mental health problems or learning difficulties may experience what was termed as experience 'diagnostic overshadowing', meaning that their reports of physical ill health were viewed as part of their mental health problem or learning disability, and therefore not investigated or treated. A Mencap report (Mencap, 2007) cited six cases of avoidable deaths among patients with learning difficulties in long term care as a result of what it termed "institutional discrimination".

3.80 It has also been suggested that the use of single shared assessments for community care services means that the process has been based, in some cases, upon the medical model of disability (Inclusion Scotland, 2005). Issues have also been raised for specific groups and the DRC (2006e) identified that people with mental health problems are sometimes denied assessment for social care services "unless they reach a high initial threshold of serious mental ill-health".

3.81 There are definitional issues with personal and domestic care (in terms, for example, of what is included). The DRC identified that the differentiation between social care, personal care and health care has led to increased complexity (DRC, 2006a) and the Multiple Sclerosis Society Scotland (2003) identified that people do not always distinguish between services when their needs cross professional boundaries. As with other service providers, it has also been noted that there can be a lack of information in suitable formats (DRC 2003), and a lack of support in accessing services.

3.82 There are also concerns about what is included in services, and group respondents suggested that health and safety reviews appear to have led to home carers carrying out fewer tasks than before (although it was noted that some local authorities now provide alternative services for excluded tasks). A range of concerns were also raised with the means of provision of home care, such as: consistency, supervision and choice of staff; lack of timely provision; and support for disabled carers. More generally, concerns were raised about the use of health of safety inappropriately to deny services or support to disabled people (DRC, 2006g).

3.83 Issues facing informal carers were also raised in group discussions relating to: the high level of expectations on informal carers; the lack of structure for informal care; and the lack of skills or training for informal carers. A recent review (Hexagon, 2007) suggested that a

significant number of informal carers may be unaware of rights to free personal care, and the burden on some may be unnecessarily large. It was also noted that some authorities may be reluctant to provide care where this is already being provided by an informal carer or another agency.

3.84 For some service users, there may be a lack of continuing contact with a social care provider after an initial meeting, making it difficult to respond to changing needs of those with a long term condition. Such service users may not match “targets” and can become “relatively invisible”, with the inaccurate assumption that they are “stable”.

3.85 There can also still be a focus, in social work services, upon the use of institutional care for some service users (Inclusion Scotland, 2005). For example, as part of the implementation of the “Same as You” initiative, the Scottish Executive identified that, in 2003, only a quarter of all adults with learning difficulties were living independently in their own homes. The DRC has identified that support at home might be more appropriate for many people in residential care. Zarb (2006) identified that the rigid application of budget rules can also lead to the use of residential care.

3.86 The wider impact of the pressures on both health and social work services (including financial pressures) has also been identified and may constrain their ability to implement the independent living agenda fully (Stirling, 2006). Rummery (2006) suggested that there has always been a tension in trying to balance providing care and tightening budgets.

3.87 It has also been suggested that assessment and provision may be based upon the nature of current services and the cost, rather than an holistic assessment of needs (Inclusion Scotland, 2005). Respondents to this research suggested that a “needs-led” service is, in effect, actually a “budget-led” service. It was also suggested that there is often a low level of involvement of disabled people in their assessment, and service users’ views may not be taken into account, particularly when these have financial implications. It was also suggested that disabled people may not be involved in service planning more generally.

3.88 Resource issues also affect the nature of some support, and some home care recipients were receiving only a proportion of their agreed hours (described by one support organisation as the “15 minute hour”). One of the DRC papers in the Disability Agenda (DRC, 2007b) noted that demand for social care outstrips supply, and projections

provided by one local authority to this research suggested that the number of referrals for aids and adaptations would rise from around 10,000 per year in 2005, to more than 20,000 by 2016. Projections developed by the Joseph Rowntree Foundation suggest that spending on community care would have to rise by 315% in real terms by 2051 to meet demographic changes.

3.89 Hexagon (2007) noted that local authorities may be operating procedures designed to assess whether an individual's needs meet certain thresholds before providing any care. Some were reported to operate a limit on the amount of free personal care which could be provided. Material from this study supported the view that local authorities have to prioritise services, sometimes based on an assessment of need and risk, and, in some cases, only people falling into the highest priority bands will receive support in the short term. A DRC paper (2007b) noted that the number of disabled people over 65 receiving home care in Scotland has fallen since 1998.

3.90 Concern was also expressed in this study that hospital-based OT services were failing to provide equipment required by disabled people on discharge from a short stay in hospital, where the need was seen to be temporary. Respondents had to buy equipment themselves, or borrow this from others. It was also suggested that people were being discharged earlier than they wished after operations, or before necessary equipment had been installed in their homes.

3.91 It has also been suggested that, although social care service providers may provide help and assistance with "obvious" issues (such as adaptations), they may be less aware of individual needs in other areas which support independent living, such as employment (Multiple Sclerosis Society Scotland, 2003). It has also been noted that services are not always provided in a way that enables them to offer access to support with issues such as employment, leisure etc.

3.92 There are some barriers in the actual legislative framework for community care services (Morris, 2004a; Stirling, 2006). It has been identified that the focus on the duties of providers can lead to a loss of focus on the promotion of rights and entitlements for users. Health and social care provision have been based upon an assumption of dependency which can be difficult to overcome, despite changes in focus in some recent documents (PMSU, 2005; Gillinson et al, 2005), and practice does not always reflect the stated commitment to change. Zarb (2006) suggests a persistent common view of social care which

identifies disabled people as “passive recipients of care” rather than “active citizens facing practical barriers to participation in the social and economic life of the community”.

3.93 Services are defined in terms of “care” rather than “support”, implying a particular view of the nature and purpose of provision, and Zarb suggests that disabled people have few effective rights in these circumstances. This makes it difficult to ensure that services which are provided are those which meet the needs and wishes of recipients. The DRC independent living discussion paper also identified a lack of legal recourse where an individual is forced to live in an institution against their wishes.

3.94 There are also barriers in the involvement of different organisations in health and community care provision, such as:

- Differences in approach, and different considerations by different staff.
- Health and social care services can operate to different principles, and similar services can be administered on different grounds (PMSU, 2005).
- The involvement of different services can lead to a further focus on cost rather than effectiveness (Gillinson et al, 2005).
- There can be a lack of agreement between health, social work services and other organisations about who has responsibility for addressing an issue, with some remaining delineation of responsibilities (PMSU, 2005; Gillinson et al, 2005).
- Budget holders can be “nervous” about the type of pooling of resources which can enable independent living (SQW, 2007).

3.95 There can also be a lack of co-ordination within individual services, with different parts addressing different needs, as well as inflexibility in provision (PMSU, 2005). Some individual respondents to this research, for example, noted specific aspects of provision which they considered to be particularly inflexible, or with which they had experienced problems. Such inflexible provision can remove disabled people’s choice about basic issues (such as, for example, the time at which people get up, when they wash, eat, use the toilet etc.). It can also remove their choice about who provides assistance with these activities (Scottish Executive, 2006a).

3.96 There are also inconsistencies in charging policies between different local authorities (Inclusion Scotland, 2005). Concerns have

been raised with the use of means testing and the imposition of charges for social care services (which are seen to contradict the principles of independent living and equality). This has been identified as “double taxation” and may also impact on family relationships. A number of individual respondents also identified that the nature and level of the care provided can vary by area, and the level of provision of support can vary to groups of people with different impairments.

Direct Payments and Independent Living Fund grants

3.97 Findings relating to Direct Payments suggest that:

- The implementation of Direct Payments in Scotland has been slower than is the case in England (Witcher et al, 2000; Pearson, 2004).
- There remain many disabled people who do not use Direct Payments¹⁹ or who are prevented from accessing these.
- There has been great variation in the number and proportion of disabled people using Direct Payments between local authorities in Scotland (Riddell et al, 2006a) and the Scottish Executive’s statistics (Scottish Executive, 2006h) illustrate this.
- The average value of payments varies widely, with the average level of payment in the highest spending authority more than 5 times that in the lowest spending authority, leading to the suggestion that this constitutes a “postcode lottery” (National Centre for Independent Living, 2006b).
- Some group participants suggested that there are still inconsistencies in assessments within individual local authorities.
- Some disabled people are less likely to have access to Direct Payments than others (The Rowan Organisation, 2005). These may include: those awaiting hospital discharge; people with mental health problems; people with learning difficulties and autism; people from ethnic minority communities; and people with dementia.
- A number of respondents identified limitations to the availability of the ILF (e.g. to people aged 66+; and for some forms of cover).

¹⁹ Gillinson et al (2005), however, note that there is a danger that the number of recipients of Direct Payments is seen as a measure of their effectiveness, rather than the “quality of life” outcomes.

Although it is acknowledged that some people may choose not to access Direct Payments, respondents identified many barriers which constrain their use amongst those who do wish to do so.

3.98 A range of reasons for these findings has been suggested. For example, it has been noted that the timing of Direct Payments legislation may have had some impact upon its implementation, as it coincided with other new legislation and changes to Scottish Executive funding priorities (from community care to acute health care). It was suggested that this, in turn, led to local authorities focusing on protecting their services rather than developing new initiatives (Gillinson et al, 2005; SQW, 2007 forthcoming).

3.99 The lack of infrastructure to support Direct Payments has also been identified. Direct Payments Scotland closed in 2005 (DRC, 2006a) and there can be a lack of a local structure for implementation. There is also, as noted, limited availability of information, advice and advocacy support for individuals, and user-led organisations may lack capacity to tender for provision, or may not be allowed to have an advocacy role when tendering. There can be a consequent lack of focus on peer support (particularly in terms of meeting emotional support needs), and empowerment (National Centre for Independent Living, 2006).

3.100 A view was expressed in the group discussions that service users who “go it alone” and do not seek support are less likely to obtain all of the care they require (although, in fairness, information providers tend to recommend that prospective users seek support prior to application). Other gaps in local services can also mean that Direct Payments do not change the quality of support for individuals (DEMOS, 2006).

3.101 The Commission for Social Care Inspection (2004) identified a lack of clear information for potential users of Direct Payments and the Multiple Sclerosis Society (2006a) identified that many people are not fully informed, and literature sometimes presents Direct Payments as being “complicated and demanding”. The provision of information by local authorities can also be off-putting, and group participants identified that obtaining information can be difficult. It has been suggested that there is still a general lack of understanding and awareness of Direct Payments (Joseph Rowntree Foundation, 2004a) and confusion about what they involve (The Rowan Organisation, 2005).

3.102 There has been no political “championing” of Direct Payments in Scotland (Riddell et al, 2006c). The same report noted that the “political

orientation of local councils”, geographical and demographic factors can all have an impact on local responses to Direct Payments. There have been no targets for local authorities (Riddell et al, 2006a). There can be a lack of commitment to Direct Payments at a senior staff level (National Centre for Independent Living, 2006), and SQW (2007) suggest that some local authorities may be reluctant to support Direct Payments. There have been some concerns amongst local authority workers about the implications of Direct Payments for their jobs (Gillinson et al, 2005) and concerns about terms and conditions for Personal Assistants (Riddell et al, 2006a).

3.103 Other difficulties with staff have been identified as including:

- That some staff base their approach to Direct Payments upon stereotypical assumptions (The Rowan Organisation, 2005). “Restrictive or patronising attitudes” can impact upon who is given access to Direct Payments (Commission for Social Care Inspection, 2004).
- Some staff and authorities do not fully understand or promote independent living (DRC, 2006a), or may be reluctant to promote Direct Payments, or do not implement them in a way which maximises choice and control (Inclusion Scotland, 2005).
- Difficulties in changing the basis of assessment from whether someone is eligible for a service to a focus on their needs (PMSU, 2005).
- Difficulties for social work staff in reconciling their conception of “risk” and their “duty of care” in consideration of Direct Payments (National Centre for Independent Living, 2006).
- Reluctance to shift the balance of power to service users (Commission for Social Care Inspection, 2004).
- Opposition from some to Direct Payments in principle (respondents).
- Concerns about the quality of care offered by some providers (Riddell et al, 2006b).
- Problems in moving to holistic assessment, continuing to base this upon personal care, rather than a wider range of requirements (NCIL, 2006).

3.104 Such factors can lead to those responsible for co-ordinating care being selective in offering Direct Payments (Spandler and Vick, 2004), or failing to encourage their use. It was clear from the discussion groups

that most participants in receipt of Direct Payments felt that the process of being accepted was unduly difficult.

3.105 Problems relating to resource issues have also been identified. It has been suggested that there was a lack of provision of specific additional resources to local authorities and others to support the implementation of Direct Payments (Direct Payments Scotland, 2003; Gillinson et al, 2005; DRC, 2006a). There was no “Direct Payments Development Fund” equivalent, and although the Scottish Executive did invest resources in implementation, it was suggested that they may not have been aware of how local authorities used these. It was suggested that there was a specific lack of investment in support organisations.

3.106 The implementation of Direct Payments also required the input of local authority resources (Riddell et al, 2006a). It has been suggested that some have not moved funds from traditional services to Direct Payments (Riddell et al, 2006b). Block funding of some services, and pre-allocation of budgets to “traditional” services can lead to inadequate budgets for Direct Payments (The Rowan Organisation, 2005). Riddell et al (2006c) also noted that “the relative ease or complexity of local purchasing mechanisms” impact on implementation.

3.107 Concerns have also been raised amongst local authorities about financial accountability, and amongst staff about the paperwork involved (Riddell et al, 2006b). Some participants in the group discussions felt that their Direct Payments were based more on the local authority’s ability to pay than their need. Some local authority guidance makes clear that Direct Payments, to be accepted, must be as cost-effective as direct provision, suggesting that Direct Payments are not being viewed as a rights issue, but remain conditional on costs.

3.108 A wide range of different budgets can be required by an individual for the provision of all appropriate support (PMSU, 2005) and Direct Payments do not always provide a response which is completely holistic. Particular difficulties were also identified with the definition and implementation of “with support”. One respondent also considered it inappropriate to have centralised (ILF) and local (Direct Payments) provision, rather than all funding being provided at a local level. It was also suggested that there may be benefits in having an independent external funding body.

3.109 A large number of concerns were expressed by participants about service users being expected to make contributions towards their packages of care. These included:

- That this provided little incentive to work, or to progress to a better job, as any increase in pay would be clawed back.
- Concerns with the process of assessment, and specifically the family expenses which could be taken into account, and the fact that spouses' or partners' incomes were also assessed. (Anecdotal evidence was provided of cases where Direct Payments users' spouses had given up work as it was considered uneconomic for them to continue due to the level of contribution they were expected to make to the package.)
- A concern that policy makers were unaware of the distinction between benefits (which are reserved) and community care contributions (which are devolved) which may lead to incorrect assumptions about the locus of responsibility for issues such as users' contributions to packages.

3.110 There can also be some difficulties for service users with becoming a purchaser of support through Direct Payments (PMSU, 2005; Riddell et al, 2006a; Department of Health, Social Services and Public Safety, 2005; Rummery, 2006). These include that:

- There can be difficulties in recruiting and retaining staff (with particular difficulties evident for disabled people from ethnic minority communities, and those in rural areas).
- Not all disabled people want to take on the responsibility of being an employer.
- As well as general employment costs, Direct Payments users employing more than 5 personal assistants have to offer the option of a stakeholder pension arrangement.
- Some elements of the use of a 'market' approach to supporting disadvantaged groups are not always empowering.
- Policies and procedures may be complex.
- There may be concerns about emergency cover.
- There may be concerns about managing Direct Payments.
- Respondents described the process as "bureaucratic" and "time consuming".

3.111 Most participants in the group discussions directly employed Personal Assistants although most had, at some time, employed

agencies to provide support. Some were concerned that agencies appeared to lack flexibility, and that users were no more in control of their care packages than when they received local authority care. Some expressed concerns about the lack of training for Personal Assistants, and perceived variations in the skills and knowledge of agency staff. One suggested that it was difficult to plan for the future, due to the uncertainty of availability of funding, and that there could be gaps in the funding provided for an individual's care.

3.112 Variations between areas in relation to a number of factors were also identified as a barrier. Group discussions identified variations in the nature of provision, as well as specific issues relating to the payment of expenses for Personal Assistants. It has also been suggested that there can be problems in retaining support packages on moving to another area, and a small number of participants suggested that they felt scared to move, in case a significant aspect of their care package changed with a fresh assessment. One participant in a group discussion also identified anomalies as a result of their moving from an English to a Scottish local authority area. There may also be differences in how Scottish Executive guidance is interpreted.

3.113 Respondents suggested that Direct Payments are not as flexible in practice as they are intended to be (e.g. in dealing with short term, or changing needs). All of these factors can lead to the situation where the intention of the development of Direct Payments is not reflected in practice (Commission for Social Care Inspection, 2004).

OPPORTUNITIES FOR ECONOMIC AND SOCIAL PARTICIPATION

3.114 There are also barriers for disabled people in some aspects of economic and social participation.

Employment

3.115 There is clear evidence of existing inequality in employment for disabled people, including that:

- Disabled people have a poorer employment position relative to non-disabled people.
- Disabled people are less likely to be in work than non-disabled people (Scottish Executive, 2005g).

- Almost half of disabled people of working age are economically inactive compared to 15% of non-disabled people (PMSU, 2005).
- Disabled people are more likely to be dependent on benefits (Scottish Council Foundation, 2005), with an employment rate which is much lower than non-disabled people (although the rate rose between the late 1990s and 2004).
- Disabled people find it more difficult to secure employment than is the case for other members of the community (DEMOS, 2006).
- Disabled people may be discriminated against if they disclose an impairment (DRC, 2007c)
- Rates of job retention are low for disabled people (PMSU, 2005).
- Many disabled people find it difficult to sustain work if their circumstances change (The Scottish Parliament, 2006a).

This suggests that there could be a significant economic impact in terms of benefit savings and tax gains if independent living were to be implemented on a wider scale.

3.116 Many aspects of policy and practice have been identified as having an impact upon this situation. A lack of focus in some key organisations on equalities work, on disability issues and on independent living has been raised specifically in relation to economic opportunities. The report of the Scottish Parliament's Disability Inquiry (The Scottish Parliament, 2006a) identified that enterprise agencies in Scotland have a limited focus on the Equality Strategy. Gillinson et al (2005) also noted that few people working within the system of provision to enable disabled people to work operate to the principles of independent living.

3.117 Differences in focus and priorities between organisations involved in providing support to enable disabled people into work have also been identified (The Scottish Parliament, 2006a), with a tension between policies which encourage people to enter employment and others which make it difficult to do so (Gillinson et al, 2005). Disabled people may view moving to employment as complex and risky (e.g. in terms of the health impact, the impact on benefits etc.) and may not be aware of the rules nor financial incentives relating to returning to work (PMSU, 2005).

At a practical level, many support services are not organised in a way that enables users to participate fully in work, or in education or training. For example, a disabled person in work may require support by 8.00am, and a service provider may not be able to guarantee this.

3.118 There are also a number of particular problems with employment-focused support (PMSU, 2005; The Scottish Parliament, 2006a). These include that:

- Intervention to enable people into work is often undertaken after someone has spent a long time out of work.
- There can be problems with assessment.
- The development of employment support has been fragmented and varied, and there can be duplication.
- There can be a lack of knowledge of services amongst disabled people.
- Some services can face funding problems.
- Disabled people may be directed to voluntary work rather than open employment.

3.119 Issues have also been raised with Access to Work (Gillinson et al, 2005; PMSU, 2005; Scottish Executive, 2006a), including:

- Confusion about the ownership of equipment and constraints to moving jobs.
- A lack of linking of assessment and provision of workplace adjustment and equipment to other support which people require in other aspects of their lives, which impact upon their ability to work.
- Problems with waiting times for provision.
- Low awareness of the scheme.
- Changes to contracts without notice.
- Management difficulties for employers.

3.120 General concern was also expressed in some group discussions that the process of obtaining Access to Work funding seemed to be a “struggle”. One described it as “worse than useless” and identified it as a barrier to the recruitment of disabled people by smaller organisations.

3.121 There are also concerns about the roll-out of Pathways to Work, and the implementation of Workforce Plus, including that they will focus on a small number of disabled people such as new IB claimants and

disabled people closest to the labour market, as well as those living in the particular areas covered (The Scottish Parliament, 2006a).

3.122 Some problems have also been identified with the New Deal for Disabled People (PMSU, 2005), such as: limited awareness of this; a focus amongst job brokers on meeting targets, leading to a concentration on those who are most “work ready”; and limited links between brokers and potential employers.

3.123 The Welsh Assembly (2007) identified issues with work experience, and a number of disabled people who were involved in the policy review “had a number of stories about meaningless work experience opportunities”. The same report identified a number of barriers to self-employment, such as: limited work experience among young disabled people; a high level of dependency on benefits; lack of accessible information; lack of accessible business support services; the lack of support to empower people to communicate their needs; and discouragement in schools and colleges of considering self-employment.

3.124 Attitudes and understanding may also impact upon employment opportunities. For example, Jobcentre Plus advisers may have problems dealing with complex disability issues, and may “match” disabled people to inappropriate jobs (PMSU, 2005). Disabled people may lack the confidence to apply for jobs or seek promotion (The Scottish Parliament, 2006a) and can face negative attitudes (DRC, 2006b). Amongst employers, there can be difficulties in engaging SMEs and a lack of awareness amongst some employers of disability issues, the law and the needs of employees (PMSU, 2005; The Scottish Parliament, 2006a). Recent research for the DRC carried out among social workers, nurses and teachers identified that disabled people may face discrimination if they choose to disclose mental health problems or hidden impairments (DRC, 2007c). Employers can also perceive a risk to them in employing a disabled person (Roberts et al, 2004).

3.125 There is a lack of support, information and incentives for employers to recruit and retain disabled people, and the support which is available comes from a range of sources (PMSU, 2005; The Scottish Parliament, 2006a). There can be a lack of partnership working between agencies and employers, and limited flexible recruitment or working practices (The Scottish Parliament, 2006a). Barriers in other areas such as education, training, transport, housing etc. can also compound difficulties in securing and retaining employment (DEMOS, 2006).

Education and training

3.126 In relation to education and training, it has been identified that:

- Disabled people often have poorer experiences of education and training than non-disabled people (The Scottish Parliament, 2006).
- The educational experience for many disabled people is one of exclusion (Inclusion Scotland, 2005).
- Disabled people generally experience poorer outcomes from education than non-disabled people (Scottish Council Foundation, 2005).
- Disabled people are likely to have fewer qualifications than their non-disabled peers (Scottish Council Foundation, 2005).
- Disabled people are more likely than non-disabled people to have no educational qualifications, as well as being less likely to have advanced qualifications (PMSU, 2005).
- In “special schools” in England almost two thirds of pupils were not entered for GCSEs or national vocational qualifications, compared to only 4% of pupils in mainstream schools (DEMOS, 2006).
- Applications by disabled people for university places are proportionately lower than for non-disabled people in the UK (DEMOS, 2006).
- Disabled people benefit less than other members of the community from learning (PMSU, 2005).

3.127 There are also problems with physical access, and many secondary schools are not fully accessible (DEMOS, 2006), with only slow change towards the inclusion of disabled children and young people in mainstream education (DEMOS, 2006). Barriers to further and higher education include limitations to: planning; careers advice; employability skills development; support for students with complex needs; accessibility, support and knowledge in institutions; expectations; funding; and the implementation of relevant legislation (The Scottish Parliament, 2006a). The Scottish Parliament’s Disability Inquiry also identified that some disabled people repeat college courses year after year, or are on course described as having little or no educational or vocational outcomes. These were described by a contributor as “pretendy” courses, and by another as “the new basket weaving”.

3.128 As with employment, mainstream support services may be unable to provide support at times necessary to support attendance at education or training. Disabled people do not always access information about educational choices (The Scottish Parliament, 2006a) and are often unaware of the support, information and assistance which can be available to them. There can be delays and difficulties with support provision at transition times in lifelong learning as a result of problems with access to information and advice, support and adjustments (Scottish Council Foundation, 2005). The Welsh Assembly (2007) also identified that education transition plans could be “superficial” and were not always “followed up on an inter-agency basis”. Where there is provision of support and equipment within education and learning, it is often linked to a particular setting and requires a new application to a different provider when a disabled person moves to another setting (Scottish Executive, 2006a).

3.129 As in other policy areas, there are also barriers with attitudes. Staff may have difficulties in accepting a changing philosophical approach, and there can be resistance to, and confusion about inclusion in education from professionals and parents (Inclusion Scotland, 2005). Some staff lack training in disability issues and there is, for example, no requirement for teachers in mainstream schools to have disability equality training, nor to have the skills to work with children with particular impairments. There is also evidence of negative attitudes from others, and disabled children and young people may experience bullying (Connors and Stalker, 2002) or other problems at school and may have limited aspirations (Capability Scotland 2003b). Disabled people may also face negative attitudes to accessing training (DRC, 2006b).

3.130 There are also specific examples of the lack of recognition of independent living in policy and strategy documents relating to education and training. Some (e.g. The Lifelong Learning Strategy; and “Lifelong Partners”) make little or no specific reference to disabled people, and some are limited in their coverage (e.g. “More Choices, More Chances”; “Partnership Matters”) (The Scottish Parliament, 2006a).

Leisure, social and public life

3.131 There is also evidence of a lack of equal access by disabled people to leisure and social activities, and public life. For example:

- People who have an impairment or long term illness feel less involved in their local community than those who do not (Scottish Council Foundation, 2005).
- Disabled people can feel isolated, with a lower level of participation in the community than non-disabled people (The Scottish Parliament, 2006a).
- Disabled people are often excluded from a wide range of leisure activities, including more and less active pursuits (DEMOS, 2006).
- Many social venues (e.g. pubs, clubs and restaurants) do not have appropriate access (DEMOS, 2006).
- Many disabled people are denied access to services and facilities as a result of an inappropriate use of health and safety legislation (DRC, 2006g).
- More than two thirds of young disabled people considered themselves to be unable to participate in most of the activities which their friends undertook (DEMOS, 2006).
- Young disabled people spend less time taking part in sport than do non-disabled young people (DEMOS, 2006).
- Disabled people are less likely than non-disabled people to hold public appointments (Scottish Council Foundation, 2005; DRC, 2006c), to be involved in public life, to be included in the democratic process and to be included in community activities.
- The general lack of disabled people in positions of authority, not only amongst MSPs, but also amongst local elected members and those in senior positions in public authorities was raised in the group discussions.
- Disabled people are less likely to be involved in volunteering (Scottish Council Foundation, 2005; DRC, 2006c), which has been identified as one means of enabling people to participate in social activity, contributing to their community and developing employment-related skills and experience (ODI, 2006).
- Many home activities are inaccessible to some disabled people.

3.132 The demand for facilities from disabled people is increasing, partly due to improved access. This, in turn, is creating pressure, and it is clear from projections undertaken for the Futures Project (Scottish Executive, 2006l) that there will be sharp increases in the numbers of people in older age groups who will face an extended period of retirement, often facing some level of ill-health or impairment. This suggests that the demand to provide accessible activities will increase.

3.133 There can be a range of barriers in facilities, which can be compounded by barriers discussed earlier in relation to the built environment, transport etc. Additionally, activities are not always available at appropriate times, and there may be limited choice for disabled people (The Scottish Parliament, 2006a). Many sport and cultural activities also face funding problems. As with access to health and community care, disabled people are increasingly finding themselves considered by providers to be a health and safety “risk” and are being denied access to buildings and services (DRC, 2006g).

3.134 Gaps in the provision of appropriate support to individuals have been identified earlier, and many disabled people have to rely on family members and volunteers to enable them to go out (The Scottish Parliament, 2006a). Participants in group discussions suggested that some local authorities take a limited view of what they will support through Direct Payments, and there were examples of refusal to support assistance with social activities or voluntary activities.

3.135 Again, attitudes can be a barrier to participation and, for example, disabled people are sometimes discouraged from volunteering. There can also be confusion about issues such as the impact of volunteering upon benefits. The Disability Inquiry (The Scottish Parliament, 2006a) also identified a general lack of awareness, amongst those providing facilities, of disabled people as a group of customers. It also suggested that there can be a lack of understanding of other issues which impact on participation in activities, such as health and safety.

3.136 Within the home (in addition to issues identified earlier in relation to the environment), DEMOS (2006) noted that the equipment which is available is unsuitable for many disabled people. For example, household domestic appliances may not be usable, and the DEMOS report quoted a survey which showed that hardly any could be “unreservedly recommended” for use by disabled people.

3.137 As has been found in other policy areas, it has also been identified that strategic documents relating to the provision of leisure and other activities do not always make reference to disabled people (The Scottish Parliament, 2006a). Again, the impact of these issues is to constrain access by disabled people to full participation, and to limit their achievement of independent living.

Income

3.138 Disabled people also face inequality in their income, which is closely linked to barriers in employment, education and training. The level of income, in turn, has an impact on access to housing, transport etc. Some of the issues relating to the financial position of disabled people include:

- In a survey for CAB Scotland, it was identified that disabled people were more than five times as likely as the general population to be in financial difficulty (CAS, 2006). A number of the respondents to this research suggested that their level of income was poor.
- The income of disabled people has been found to be, on average, less than half of that of non-disabled people.
- Disabled people face higher than average costs (Scottish Council Foundation, 2005) and a quarter of respondents to the CAB Scotland survey suggested that they could not meet their needs as a result of costs.
- Disabled people are up to three times more likely to exit from work than non-disabled people, and those in work are more likely to reduce the level of their participation (Rigg, 2005).
- Many disabled people are reliant on benefits unnecessarily, as other forms of independent living support are not in place (SQW, 2007).
- Disabled people are less likely than non-disabled people to have savings or investments (Scottish Council Foundation, 2005).

3.139 Some of the barriers which impact upon these issues relate to those outlined earlier in education, training and employment and will not be reiterated here. For disabled people in employment, the DRC identified that their average gross hourly pay was around 10% less than that of non-disabled people (DRC, 2004a). Rigg (2005) suggested that disabled people were less likely to be at the upper end of pay scales, or to enjoy the same rates of income growth as non-disabled people, also noting that income differentials between disabled and non-disabled people are widest at lower rates of pay. The Scottish Council Foundation (2005) suggest that poverty and disability are interlinked, as causes and consequences of each other, with many disabled people living in deprived communities, with poor access to services.

3.140 Some of the groups expressed concern that, as a result of high costs, low pay and the level of contribution to care, disabled people find it difficult to save. There was also a concern that savings are taken into account in means-testing benefits and community care contributions. This also has knock-on issues in that disabled people are less likely to have access to additional savings, or additional pensions once reaching 65, and are, therefore, more likely to have to depend on the state retirement pension and pension credit (which was identified by Help the Aged as “ferociously difficult to understand²⁰”).

3.141 The benefits system has also been seen to create barriers to income (in relation to employment). These include, for example, concerns about loss of benefits if disabled people undertake work and uncertainty about the benefit situation for people undertaking part-time or low paid work (Scottish Executive, 2005a). Problems have also been identified with particular aspects of the benefit system, such as the use of GPs as the main route to Incapacity Benefit. These include, for example: the use of the medical model for assessment; a lack of information; and their lack of effective links to routes to employment (PMSU, 2005). It has also been suggested that it takes a long time for an assessment of disability status, which can consequently hinder a return to work (PMSU, 2005). The same report suggested that assessment for benefits does not assess a person’s underlying capability for work, nor the steps which might enable them to return to work.

3.142 It has also been suggested that the level of benefit provision is insufficient to reflect the additional costs faced by disabled people who, consequently, do not enjoy an equitable quality of life (Smith et al, 2004). The Multiple Sclerosis Society Scotland (2003) highlighted that Disability Living Allowance is not sufficiently sensitive to fluctuating conditions. There can also be a lack of awareness of entitlements, and a concern was expressed in one of the group discussions that awareness of DLA was low. A specific concern was also expressed that recipients were being encouraged to appeal their assessments to secure a higher rate, without being made aware that their current support could be withdrawn.

FUNDING AND RESOURCES

3.143 It has also been suggested that there are a range of problems with resources, which present further barriers to the development of

²⁰ <http://www.helptheaged.org.uk/en-gb/AdviceSupport/FinancialAdvice/Pensions/PensionIssues>

independent living. Generally, it has been suggested that insufficient funding has been made available to support independent living, with a lack of provision of additional funding from central government. There is also a general lack of recognition of the potential economic benefits of supporting independent living.

3.144 Some stakeholders in the Scottish Parliament's review of equalities work (RHA, 2006a) identified limitations to funding for taking forward equalities work, such as: the general lack of resources for equalities initiatives; the short term focus of some funding; difficulties in accessing funding; and capacity issues for organisations. Some also suggested that the relationships between the Scottish Parliament, Executive and local authorities can cause problems with funding for equalities issues, with each suggesting that others are responsible for funding issues, leading to implementation difficulties.

3.145 It has also been suggested that there has been a gap in resources to develop and sustain disabled people's organisations, including those providing information, advice and advocacy. Many face problems with resources, which impact upon their capacity and their ability to participate in competitive tendering (thus limiting their ability to be involved in promoting independent living). Resources for user-led organisations also often focus on specific areas, rather than taking an holistic approach (Gillinson et al, 2005).

3.146 Problems have also been identified with the provision of resources in individual services and policy areas, with a suggested lack of specific resources for independent living at a local level. Many services face financial pressures, and competing demands on local authority (and other organisations') budgets can lead to the lack of priority for independent living, and a lack of resources. There have also been reductions in some relevant funding (such as Supporting People).

3.147 Some specific funding issues were identified in the discussion of Direct Payments, including: lack of provision of specific resources to provide support; lack of accountability of local authorities in using additional resources; lack of movement of funds from traditional services to new arrangements; issues with block funding and pre-allocation of budgets; the relevance of a wide range of budgets to meeting an individual's needs; and the limited funding covered by Direct Payments. It has also been suggested that the ILF can lead to financial pressure to favour residential provision. Those whose weekly support costs exceed

a particular amount are ineligible, and their local authority would require to meet the entire support cost for them to live at home.

3.148 As well as resource gaps, it has been suggested that existing resources are not always used most efficiently (PMSU, 2005). It has been suggested that fragmentation of service provision can lead to resource problems, and the failure to meet the needs of a disabled person by one public body can lead to costs for another. Duplication of functions can also lead to inefficient use of resources (PMSU, 2005). The Scottish Executive (2006b) has noted that the existence of complex arrangements for the governance and funding of services can lead to difficulties for local authorities and their planning partners in providing integrated services which centre on the needs of service users.

3.149 As noted, it has also been suggested that there has been a limited focus on the potential economic benefits of independent living (Inclusion Scotland, 2005), despite the significant potential for such benefits to accrue to the state and individuals. It is often assumed that independent living is expensive, whilst it has been suggested that this is not the case. The promotion of independent living may actually lead to potential savings, such as reduced demand for services at a later stage; increased economic activity and tax revenue; and lower and more efficient spending on services (Gillinson et al, 2005). SQW (2007) note that:

“Published material to date indicates that the delivery of independent living support to disabled people and to older people is more cost effective, or at least no more expensive, than traditional care provision.”

3.150 The costs of failing to enable independent living are not, however, considered in allocating public resources, and the wider costs of dependency are not examined in decisions about health and social care. There can be a failure to see the provision of resources to independent living as involving economic and social investment (PMSU, 2005) and there is a lack of data on the costs and benefits of independent living support compared with “conventional” support (SQW, 2007).

3.151 At an individual level, there are variations in the provision of funding for independent living to service users themselves (Inclusion Scotland, 2005). Variations have also been noted between authorities in funding, eligibility and charging policies for community care (Inclusion Scotland, 2005). Again, all of these factors can reduce the impact of

some of the more positive developments towards independent living highlighted in Section 2.

OVERVIEW

3.152 Whilst there have been many changes which impact on independent living, a range of issues continue to limit participation by disabled people. A key factor is that, overall, while disabled people have rights in some areas, there is no overall right to independent living. This makes it more likely that barriers which might otherwise be removed remain, and that mainstreaming of independent living is constrained.

3.153 It is suggested that the starting point for any strategy to promote independent living must be to identify ways of developing positive opportunities for this, addressing the problems highlighted. Given that independent living involves all aspects of disabled people's lives, it is important to tackle the wide range of issues discussed, to promote and sustain independent living as the most appropriate way forward for disabled people in Scotland. In the light of the evidence on the changes to Scotland's population, it is also clear that the way forward must be robust and sustainable in the long term.

3.154 The following section considers some of the changes which are required, and the ways in which a strategy might build upon, and develop from the findings of this report.

SECTION 4: SUGGESTIONS FOR DEVELOPMENT

4.1 This final section focuses upon highlighting some of the changes which are seen to be required to achieve independent living in Scotland, based on the opportunities for development which may be feasible, and the barriers which need to be overcome. A number of objectives for each of the key components are identified (based on the findings which have been detailed) before some of the actions which may be required are specified.

THE IDENTIFICATION OF OBJECTIVES

4.2 The findings of the previous sections suggest that a number of objectives are required in order to support independent living.

4.3 In relation to the **political, social and service structure**, the suggested objectives are to:

- *Create a political and organisational structure in Scotland which recognises and promotes independent living and equality for disabled people.*
- *Ensure that there is a clear commitment to independent living, and that all legislation, policy and practice which develop in Scotland are consistent with the principles and goals of independent living.*
- *Promote full involvement and participation in decision-making on an equal basis by disabled people, and ensure that there is appropriate social and financial support in place to enable this.*
- *Ensure that the concepts of equality and independent living for disabled people are widely understood and supported throughout Scottish society.*
- *Develop service provision and practice which promote, support and sustain independent living for disabled people.*

4.4 In relation to the **environment**, the suggested objectives are to:

- *Develop a built environment in Scotland which is fully accessible to disabled people and enables them to use all public spaces on a safe and equal basis and to access opportunities for economic and social participation.*
- *Develop a fully integrated, affordable and accessible transport system in Scotland which enables disabled people to have full*

and equal choice of where and when they travel and to access opportunities for economic and social participation.

- *Provide public and private housing which meets the needs of disabled people and enables them to choose the location and type of their housing.*

4.5 In relation to **personal support and services**, the suggested objectives are to:

- *Provide appropriate, comprehensive and enabling personal support to disabled people, which promotes and sustains independent living.*
- *Enable disabled people to have full control of the nature of their support and the ways in which it is provided, and develop a robust system which locates control of all relevant resources with individual service users.*

4.6 In relation to developing **opportunities for economic and social participation**, the suggested objectives are to:

- *Ensure that recruitment and employment practices in Scotland enable disabled people to have equal access to employment, and that appropriate support is provided to enable them to gain, sustain and retain employment.*
- *Develop an inclusive education system that enables disabled people to participate fully and equally in all aspects of this, and develop equal access to all forms of training.*
- *Develop facilities and provision to enable full and equal participation by disabled people in all aspects of leisure, social and public life.*
- *Provide a benefits system which recognises the additional costs faced by disabled people, and meets their financial requirements, whilst avoiding the creation of additional barriers to participation in other aspects of life.*

4.7 In relation to **funding and resources**, the suggested objectives are to:

- *Recognise the economic benefits of independent living and ensure the provision of adequate long term sustainable resources to support all of the developments which will be*

required to enable full choice and participation by disabled people in all aspects of their lives.

ACTIONS REQUIRED

4.8 In order to achieve these objectives, a range of actions are suggested. Some are drawn or adapted from recommendations in some of the key documents highlighted, some have emerged from the literature and some from contributions to this research. Many apply across policy and practice areas. These are not a comprehensive account of all of the changes which are required to achieve independent living in Scotland, but provide a starting point and some examples for further discussion of actions which might form part of a future strategy.

4.9 Actions are suggested in the following areas:

- Creating appropriate decision making structures.
- Making policy and legislation to meet the needs of disabled people.
- Ensuring that reserved matters reflect the needs of Scotland.
- Ensuring the inclusion and empowerment of disabled people.
- Delivering information, advice and advocacy.
- Addressing attitudes and behaviour.
- Developing effective service standards and service outcomes.
- Delivering services to meet the needs of disabled people.
- Funding and sustaining independent living.

4.10 The promotion of independent living by all organisations is considered to be central to taking disability equality forward and it is acknowledged that, in many of these areas, work is already underway in some organisations. Taken together (and alongside other work to promote disability equality), it is suggested the changes which are proposed would enable the choice, control and freedom which are required for independent living in Scotland.

4.11 The implementation of these changes will require input from a range of participants, including: central and local government and other agencies; private and voluntary sector organisations; disabled people; and other members of local communities. There is a need for all of the relevant organisations to ensure that they identify the implications of independent living for their own service, and the implications of these suggested actions for them.

4.12 All of the developments should be taken forward in conjunction with disabled people. The work which is undertaken should also take account of work taking place across the UK. The actions required are detailed below, with examples, where appropriate.

Creating appropriate decision making structures

4.13 There is a need to create appropriate structures for decision making in Scotland which support independent living. Actions could include to:

- *Establish an Independent Living Task Force in Scotland at an early stage, and:*
 - Develop appropriate means of the Task Force engaging with disabled people.
 - Develop an appropriate monitoring and reporting structure.
 - Identify and clarify its remit (e.g. the development of a strategy; implementation of recommendations from key relevant reports; and general oversight of independent living developments).
 - Identify appropriate members of the Task Force (e.g. key organisations involved in social and public policy in Scotland and those with expertise on disability issues, with a high level of direct involvement of disabled people).
- *Develop clear links between the Task Force and other key stakeholders at a UK, national and local level including, for example:*
 - The Scottish Parliament and Scottish Executive.
 - The CEHR and SCHR (and the DRC for the remainder of its life).
 - The Office for Disability Issues and the Independent Living Project Team in England.
 - The Department for Work and Pensions and the National Workforce Plus partnership.
 - National and local disability organisations.
 - Local authorities, partnerships and other local service providers.
- *Identify a process of input of expertise and information sharing between the Task Force and relevant bodies, and:*

- Ensure that the findings from key work cited in this report, the findings of this study and the outputs from the recently published Disability Agenda are used to inform the way forward.
- Identify mechanisms to ensure that the findings from research and policy developments in the future are taken into account.
- *Establish a cross-governmental Ministerial Group in Scotland, and mechanisms for interdepartmental work on independent living by senior officials.*
- *Monitor the development of the CEHR to ensure that this reflects issues for independent living in Scotland and raise any concerns as these arise.*
- *Consider the establishment of local independent living partnerships or other appropriate multi-agency structures (with links to other local planning structures) and:*
 - Ensure consistent work at a local level.
 - Ensure that local partnerships reflect the recommendations (above) relating to the national Task Force.
- *Develop other mechanisms for joint working between services and:*
 - Use existing joint planning mechanisms to consider independent living issues.
 - Use a range of planning arrangements, working across geographical boundaries, and involving appropriate disciplines.
 - Ensure that all local areas develop a specific appropriate infrastructure for the management of Direct Payments, with a lead officer and links between the structure for implementation of Direct Payments and other relevant local multi-agency working structures.
 - Ensure that inspection and audit are integral both to existing services, and any services which develop.

Making policy and legislation to meet the needs of disabled people

4.14 There is also a need to ensure that the principles and goals of independent living are reflected and identified in **policy and legislation**. Actions could include to:

- *Develop an independent living strategy for Scotland to underpin and guide future work, with:*

- An overall vision, key principles and objectives linked clearly to human rights and equality.
- Definitive definitions of “equality”, “independent living” and the “social model of disability” which can be adopted by organisations throughout Scotland.
- Appropriate targets, supported by an action plan with specified timetables, measurable milestones and outcomes.
- Identification of roles and responsibilities, costs and potential sources of funding.
- Arrangements for review.
- *Ensure that all policy makers and practitioners in Scotland support the overall strategic commitment to independent living and:*
 - Adopt the national strategy.
 - Adopt the definitions.
 - Adopt the concept of independent living as a fundamental human right and desired outcome.
- *Develop local independent living strategies and action plans in each area (linked to key organisations’ Disability Equality Schemes) and ensure that, as a minimum, they include:*
 - Adoption of the national vision and definitions.
 - Local targets.
 - Local action plans with service specific and cross-cutting actions.
 - Specified timetables, measurable milestones and outcomes.
 - Identification of roles and responsibilities, costs and sources of funding.
 - Arrangements for review.
- *Ensure that all relevant local partners adopt the strategy, and that they:*
 - Take ownership of actions identified.
 - Ensure that the key priorities and policy commitments are translated into concrete actions at a service level.
- *Identify independent living as a priority across services and:*
 - Provide clear and accountable leadership.
 - Express a clear commitment to this at a national and local level.
 - Translate existing commitments into concrete actions.
- *Ensure the use of the common definition of disability and appropriate language (based upon the social model and independent living), in all relevant policy and legislation.*

- *Identify, implement and enforce relevant equality policy and legislation, and other relevant policy and legislation which supports independent living, such as:*
 - The DDA.
 - The Land Reform Act (Countryside Access Code).
 - Legislation relating to hazards on pavements and parking on pavements.
 - Any legislation to prevent the abuse of designated parking spaces.
 - Housing legislation and policy, as detailed in Section 2.
 - Health and community care legislation and policy.
 - Direct Payments legislation and guidance, ensuring that these are offered to all of those who are eligible.
 - Legislation to protect and promote the rights of disabled people in education and training.
- *Consider the provisions of the Independent Living Bill and identify whether legislation is also required in Scotland to enshrine the rights of disabled people in law, including the right to independent living (and address current gaps in rights provision).*
- *Undertake ‘proofing’ and impact assessment in relation to: all draft legislation, policy and strategies; initiatives; planned developments; and reviews at a national and local level, not only for general equalities issues, but also for:*
 - The specific impact on disabled people and particular groups of disabled people.
 - Consistency with the social model of disability.
 - The impact on independent living and potential for promotion of independent living.
- *Identify and reflect the commitment to independent living at a national and local level in legislation, key policies and strategic documents and the associated guidance, such as, for example:*
 - Building standards and planning advice notes.
 - Legislation and regulations relating to signage and other issues in the built environment.
 - The National Transport Strategy.
 - Regional and local transport strategies.
 - Local housing strategies.
 - Homelessness strategies.
 - Supporting People strategies.
 - “Healthier Scotland” strategies and action plans.
 - Community care plans.

- Health and social work plans (both overarching and for particular parts of the services, such as OT services, home care etc.).
- Enterprise strategies.
- Community learning strategies.
- Education plans.
- Funding councils' plans.
- University and college strategies.
- Community education strategies.
- Lifelong learning and training strategies.
- "Let's Make Scotland More Active".
- Sport 21.
- Active Schools.
- Any strategic documents developed by Creative Scotland, and national and local tourism strategies.
- The Strategy for Equal Opportunities in the Public Appointments Process.
- Strategic documents relating to poverty and deprivation.
- Community safety and anti-social behaviour strategies.
- *Identify and reflect the commitment to independent living at a national and local level in overall initiatives such as:*
 - Public sector reform.
 - The review of scrutiny of public services.
 - The framework for auditing the Disability Duty.
 - The Multiple and Complex Needs Initiative.
 - The NHS "Fair for All" project and materials.
 - Joint Future initiatives.
 - New Deal.
 - Workforce Plus.
 - Access to Work.
 - Work to develop healthy workplaces.
 - The "Investors in People" process.
 - Any initiatives relating to "Closing the Gap".
 - Any initiatives to promote financial inclusion.
- *Identify and reflect the commitment to independent living at a national and local level in planned service developments, such as:*
 - New environmental developments.
 - Applications for land use.
 - Planning applications.
 - Town centre initiatives and developments.

- Licensing developments, trading standards and environmental health functions at local level.
- Renewal of areas.
- Low cost home ownership schemes.
- Consideration of building development plans in the private and social housing sectors
- All other relevant housing initiatives.
- The work of health promotion organisations.
- Social work and community care initiatives.
- Work to develop a supported employment framework in Scotland.
- Training initiatives.
- The development of new organisations in leisure, social and public life (such as Creative Scotland).
- Community safety and anti-social behaviour initiatives.
- *Use the Disability Equality Duty, and the preparation of Disability Equality Schemes, as a specific opportunity for designated organisations to:*
 - Make a clear commitment to the social model and to independent living.
 - Identify and specify the ways in which the actions of public bodies will enable independent living.
 - Include independent living in the process of impact assessment.
 - Ensure that local strategies of all types are linked to Disability Equality Schemes.
 - Raise standards in service provision to disabled people.
 - Monitor the effectiveness of Disability Equality Schemes in promoting independent living and measure progress against planned improvements.
- *Identify and reflect the commitment to independent living at a national and local level in reviews, such as those relating to:*
 - Scrutiny of public services.
 - The Equality Strategy.
 - Supporting People services.
 - “Partnership Matters”.
 - The Volunteering Strategy.
- *Examine organisations’ implementation of other relevant actions, and:*
 - Ensure the implementation of the recommendations of relevant cross-cutting and service-specific reports (e.g. the social work review “Changing Lives”; “Working for a

Change? The Same as You”; “The Same as You”; “More Choices, More Chances”; the Scottish Parliament’s Disability Inquiry report and the Scottish Executive’s Disability Working Group Report).

- Ensure the consistent implementation of these recommendations across Scotland.
- Identify the links between the recommendations and both the development of independent living and Disability Equality Schemes.
- Ensure that any other requirements specified in reports or policy are met.
- Incorporate the development of Direct Payments into the strategic approach to provision in all local areas, and identify these as a tool to enable disabled people to access independent living.

Ensuring that reserved matters reflect the needs of Scotland

4.15 In policy areas where some powers are reserved, there is a need to **raise any concerns** which arise which are specific to Scotland with the relevant UK government department or agency. Actions could include to:

- *Raise issues relating to employment and training and:*
 - Ensure that successful employment and training initiatives in England (including initiatives with employers) are replicated in Scotland.
 - Identify and implement actions which can be taken specifically in Scotland.
 - Support the wide range of relevant actions, suggestions and initiatives which are detailed in the PMSU report “Improving the Life Chances of Disabled People” as being required to promote access to employment or training for disabled people, and ensure that these are implemented in Scotland.
- *Raise issues relating to income and poverty and:*
 - Continue to undertake initiatives to address income and poverty in Scotland.
 - Ensure a focus in Scotland on improving access to education and employment as a means of increasing opportunities for disabled people to access an income.

- Encourage that the benefit reforms reflect and promote the need for independent living (e.g. in assessment processes, level of income etc.).
- Raise the need for the benefit reforms to reflect the additional costs faced by disabled people (including travel costs).
- Ensure that reforms recognise that there are some disabled people who will not have paid employment as an option.
- Encourage the review of benefit reforms, after a period of implementation, against the goal of independent living.
- Encourage development of the benefit system to be sufficiently flexible to enable participation in work by disabled people without financial penalties.
- Encourage monitoring of the implementation of Pathways to Work in terms of its effectiveness for disabled people.
- *Raise issues relating to transport and the accessibility of services, and:*
 - Ensure that national guidance issued by the Department of Transport meets the needs of disabled people in Scotland.
 - Identify ways where Scotland could implement DDA provisions in advance of the dates set out in the Act.
 - Monitor the implementation of, and compliance with the DDA, to ensure that it is effective in Scotland.
- *Raise issues relating to Direct Payments and monitor the outcomes of the individual pilots currently operating, and:*
 - Identify the types of funding which could / should be included in Direct Payments in Scotland and the implications of this.
 - Consider how funding relating to reserved functions might be incorporated.
 - Consider and highlight issues relating to the eligibility criteria for the ILF and any gaps in the coverage of this.

Ensuring the inclusion and empowerment of disabled people

4.16 There is also a need to develop structures and consultative processes which involve and reflect the views of disabled people and consider issues affecting independent living. Actions could include to:

- *Ensure the involvement of disabled people in all of the new structures which develop (set out above).*
- *Ensure the appropriate involvement of disabled people across policy areas at all levels, from the earliest stage, including in:*
 - Planning and drafting of legislation, policy, strategies and services.
 - Scrutiny of policy, legislation, strategies and services.
 - Review of policy, legislation, strategies and services.
 - Identification of problems and issues arising.
- *Identify the means of current representation and inclusion of disabled people, and any gaps or barriers, and promote opportunities for increased participation, through, for example:*
 - Development of the work of access panels, ensuring their consistent involvement throughout Scotland.
 - Close working with MACS, and ensuring that transport partnerships consider independent living issues.
 - Ensuring the inclusion of disabled people in national and local groups considering strategic housing issues and in tenants' and residents' groups.
 - Ensuring the involvement of disabled people in Joint Future implementation groups, Community Care Forums and Community Health Partnerships.
 - Developing local Direct Payments implementation groups and clear mechanisms for the inclusion of users' views.
 - Including disabled people in Workforce Plus partnerships and local management structures such as college boards, lifelong learning partnerships etc.
 - Developing links between disabled people and employment-related organisations.
 - Involving disabled young people in representative organisations in schools.
 - Developing work with the Disabled Students' Stakeholder Group.
 - Ensuring inclusion of disabled people on representative bodies for further and higher education.
- *Ensure the further development of representative organisations of disabled people, and:*
 - Identify and map current organisations and examine their capacity.
 - Undertake capacity building work, as required, with organisations of and for disabled people.
 -

- Address identified shortfalls in capacity, generally through improved funding.
- *Where necessary, develop new national and local mechanisms for involvement of disabled people, and, for example:*
 - Monitor the development of “Equality 2025” in terms of its role in Scotland, with a view to the establishment of a national forum to secure input from disabled people in Scotland.
 - Encourage the development of new local mechanisms for the involvement of disabled people in a range of groups and circumstances (including with individual organisations).
 - Develop and promote joint approaches to engagement with disabled people where appropriate (e.g. through the planned Public Sector Equality Forum).
 - Ensure that organisations exist to support the needs of, for example, disabled people from ethnic minority communities and disabled people in rural areas.
- *Develop further information and guidance relating to the involvement of disabled people, including, for example:*
 - Guidance relating to good practice in meaningful engagement, consultation and empowerment.
 - Guidance relating to the involvement of disabled people in specific types of development (e.g. the preparation of Disability Equality Schemes and policy documents).
 - Guidance relating to the involvement of specific groups of disabled people.
 - A protocol for the involvement of disabled people (with the provision to update and revise this in the light of any national developments).

Delivering information, advice and advocacy

4.17 There is a need to ensure that there is **information, advice and advocacy** support in place to support independent living. Actions could include to:

- *Identify the need for specific information, advice and advocacy services to support independent living, and:*
 - Conduct research into information and advice needs amongst disabled people.

- Identify and map current provision of independent information, advice and advocacy services to disabled people in Scotland.
- Identify gaps in provision generally, and gaps in provision to specific groups.
- *Ensure the development of independent information, advice and advocacy services to support independent living in all local authority areas in Scotland, and:*
 - Develop a strategic approach at a local level to providing general and specific information and advice to disabled people.
 - Ensure the development and commissioning of services where there are existing gaps.
 - Consider the best means of making provision to rural areas (including, for example, helpline support).
 - Consider the best means of making provision to specific groups of disabled people and develop intensive support provision.
 - Identify and specify minimum services which should be provided through user-led support services.
- *Develop forms of provision which address the needs of disabled people and promote good practice, including, for example:*
 - Provide “one-stop” information and support wherever possible.
 - Consider the development of a National Centre for Independent Living in Scotland and increase the coverage of local CILs.
 - Examine the current provision of Disabled Persons’ Housing Services and ensure the provision of specialist housing support in all areas.
 - Develop a range of forms of provision, including, for example: face to face support; helpline support; peer support; and “buddying”.
 - Provide timely information and support.
 - Promote a specific focus on enabling disabled people to have choice in accessing and managing Direct Payments and other support.
- *Improve access to local authority information and other (generic) information, advice and advocacy, and:*
 - Identify a central point of contact in each local authority with responsibility for disability issues.

- Develop outreach services to enable all groups to access support.
- Encourage key organisations to be exemplars of good practice.
- Support service providers in the development of their information and support which is accessible to a range of disabled people.
- Provide information about all services in a range of formats and media, following SAIF standards.
- Provide guidance on inclusive communication (as suggested by the Scottish Executive Disability Working Group), develop a website on good practice and highlight sources of expertise.
- Identify mechanisms for sharing good practice in information and support provision.
- Improve communication support, and increase the teaching and use of BSL (e.g. in schools).
- *Develop accessible information on a wide range of issues, including, for example:*
 - The availability of support.
 - Effective, accessible linked and integrated journey information for all modes of transport.
 - Availability of housing, housing rights and opportunities.
 - Health and community care rights and provision.
 - Direct Payments and ILF grants.
 - Scotland-specific information, advice and guidance on employment issues (to employers and disabled people).
 - Training materials.
 - Information to students and potential students.
 - Active citizenship.
 - The availability of benefit provision.

Addressing attitudes and behaviour

4.18 There is a need to address **attitudes and behaviour** amongst the community as a whole, disabled people and service providers. Actions could include to:

- *Develop a package of national and local measures to promote positive attitudes and address negative attitudes to disabled people, through, for example:*

- A national public awareness campaign, with strands addressing different issues, and targeting specific communities.
- Activities in local areas to support the national campaign.
- Targeted information to specific groups (e.g. employers; particular service providers) to address specific aspects of their attitudes to disabled people relating to their own role.
- *Develop work with young people, to develop their awareness through, for example:*
 - Work with children and young people to develop positive attitudes to disabled people.
 - Disability equality training in schools and identification of ways to raise awareness of the principles of independent living through the curriculum.
 - Review of the material used in schools relating to education for citizenship, with the use of this as a means of disability awareness raising.
- *Work with the media to:*
 - Promote positive and accurate reporting of disability issues and activity.
 - Promote the use of positive images of disabled people.
 - Increase the representation and visibility of disabled people in the media.
 - Provide a challenge to “myths” and inappropriate assumptions.
 - Encourage media organisations to consider their own practices (both in the material they produce and in their employment practices), encouraging them to challenge, rather than reinforce, inappropriate stereotypes.
 - Develop further guidance relating to disability issues.
 - Increase links and contact between disability organisations and the media.
- *Ensure and encourage good practice across organisations in the promotion and portrayal of disabled people, and:*
 - Include positive images of disabled people in publications by key organisations (including material not relating specifically to disability).
 - Ensure that the language used in material from all organisations is appropriate and reflects the social model of disability and the principles of independent living.

- Develop the use of positive role models and images.
- Encourage debate of independent living and disability issues.
- *Ensure that good practice guidance and information are developed, provided and disseminated widely to staff, reflecting the shared understanding of key terms. For example:*
 - Provide positive examples of good practice (such as the inclusion of disability equality training for architectural students).
 - Provide guidance about mainstreaming and other elements of good practice (e.g. of inclusive design and the management of the built environment; the benefits of accessibility in housing; the use of Direct Payments etc.).
 - Provide information on specific issues (such as the conversion of traditional packages of day care to Direct Payments; information to address specific staff concerns about Direct Payments etc.).
 - Disseminate existing guidance and advice.
- *Develop the provision of disability equality training, and understanding of specific issues, and:*
 - Ensure that the shared meanings of terms such as “independent living” and the “social model” are embedded in disability equality training.
 - Ensure that all staff are aware of the implications of independent living for their roles.
 - Improve understanding of the implications of particular impairments.
 - Improve understanding of appropriate interventions and their links to independent living.
- *Review and expand disability equality training, which is led and provided by disabled people and:*
 - Undertake capacity building with trainers.
 - Develop standards and accreditation for disability equality training.
- *Develop and promote the use of disability equality training, and:*
 - Ensure the provision of such training to all existing staff and volunteers involved in planning, provision review and inspection of relevant services.
 - Include disability equality and independent living issues in professional qualifications and training, and ensure that their inclusion is recognised by accrediting bodies.

- Include these issues as part of continuous professional development.
- Develop “accessibility” modules in university and college courses (e.g. teaching; architecture etc.) and continue to develop and extend the “Teachability Project”.
- Support and develop training in relevant issues for particular groups of staff.
- *Provide training to disabled people to help develop their capacity, and:*
 - Undertake awareness raising through information, advice and advocacy organisations.
 - Provide support to enable disabled people to recognise their own interests, skills and opportunities.
 - Enable the development of the skills required for independent living.
 - Continue to support and develop specific training focusing on Direct Payments for service users.
- *Identify other opportunities to address attitudes and:*
 - Use key changes in policy to stimulate public debate, raise awareness and promote positive views of the contribution of disabled people to society.
 - Develop increased opportunities for disabled people and non-disabled people to have contact with each other in a range of settings.
 - Use conferences, publications and other means to develop understanding of independent living and its implications.
- *Identify key research issues relating to disabled people’s experiences and:*
 - Undertake work to investigate these.
 - Disseminate the results of studies widely.
 - Identify and use a range of mechanisms for sharing information.
- *Take action against inappropriate attitudes and behaviour and:*
 - Ensure that issues affecting disabled people are considered and addressed in initiatives to combat crime, particularly harassment and abuse.
 - Ensure that the community safety and anti-social behaviour strategies and initiatives, and the work of local partnerships reflect the principles of independent living and do not create further barriers.

- Develop legislation relating to hate crimes against disabled people.
- Develop further action to combat abuse, discrimination and prejudice.

Developing effective service standards and service outcomes

4.19 There is a need for all services to develop **service standards, targets, “minimum outcomes” and outcome-based indicators**, in conjunction with disabled people, which reflect the focus on independent living. Actions could include to:

- *Develop common standards, performance indicators and guidance relating to:*
 - The nature and promotion of independent living.
 - ‘Proofing’ and scrutiny of independent living.
 - The development of work to promote independent living and human rights for disabled people.
 - Policy-specific issues and good practice (e.g. housing, transport, institutional care etc.).
- *Develop a framework of cross-cutting and service-specific goals nationally and locally, which might include, for example:*
 - Equality of mobility.
 - Increasing the availability of appropriate and accessible housing.
 - Increasing general take up of Direct Payments and take up by specific groups.
 - Increasing employment of disabled people.
 - Increasing participation in education, training, education, leisure, sport, public life etc..
- *Develop and / or review targets to support these and:*
 - Reflect them in national, regional and local strategies.
 - Identify actions and timescales to support them.
 - Monitor their implementation²¹.
- *Develop a framework of minimum entitlements and:*
 - Use these to guide the support packages provided and the provision of services to disabled people.
 - Develop a consistent approach to provision and charges Scotland-wide.

²¹ Whilst recognising, in the case of Direct Payments that the choice not to use these may be a positive outcome, and assessment should not be based on numbers alone.

- Ensure that assessments are accepted in all local authorities, with changes only in the case of material changes to recipients' circumstances.
- Develop a consistent approach to specific issues such as aspects of Direct Payments (with clear and common criteria for eligibility) and enabling participation by disabled people in sport, cultural and leisure activities.
- *Ensure specific consideration of independent living and disability equality in:*
 - Audit and inspection processes and evaluations (e.g. the consideration of Best Value; inspections such as those by HMIE; and the auditing of the Disability Equality Duty).
 - Assessment of staff performance.
 - Identification of progress against identified targets.
- *Develop inspection criteria, relevant Best Value and other performance indicators, and:*
 - Scrutinise their implementation through appropriate processes.
 - Identify mechanisms for enforcement.
- *Collect appropriate monitoring information, and:*
 - Conduct systematic research to explore the impact of policy, legislation and practice (e.g. the new Building Regulations; the effectiveness of health interventions and community care provision; supply and demand for personal assistants and other support staff).
 - Develop guidance for assessing services in terms of their impact on the promotion of independent living.
 - Carry out reviews of provision to individuals on a regular basis.
 - Develop mechanisms for obtaining user feedback, and include specific consideration of issues for disabled people in this.
 - Publish data on the provision of independent living and its integration to services.
- *Ensure that accessible and well-publicised complaints procedures are in place and:*
 - Provide a process of appeal for individuals whose choices are not respected.

Delivering services to meet the needs of disabled people

4.20 All services need to examine and develop specific aspects of their own **service provision and practice** which support independent living. Actions could include to:

- *Continue to develop needs-based strategic planning of services, and:*
 - Identify and address gaps in information about the needs of disabled people to inform all forms of service provision.
 - Consider the needs of particular areas and groups, including informal carers, disabled people from ethnic minority communities and other equalities groups.
- *Develop specific initiatives to improve service information, such as:*
 - A standard approach to the use of local housing registers, making these a requirement in all areas and considering the development of a national register.
 - Ensuring that all housing providers monitor their current stock.
- *Develop further joint working between relevant services, to promote independent living across all aspects of people's lives and:*
 - Develop joint means of assessment and provision and use single holistic assessments.
 - Undertake joint provision and monitoring of services.
 - Ensure provision by the same member(s) of staff or ongoing contact from a key worker to an individual service user.
 - Promote "one-stop" access to adaptations and ensure a consistent approach to this, with formal policies in all areas.
 - Ensure the provision of appropriate equipment, aids, adaptations and other support, by the appropriate provider, at the time when it is required, to meet individual needs.
 - Develop and improve means of open communication between services.
 - Develop links and communication with other relevant services and organisations.

- Support specific networks, including the Scottish Personal Assistants Employers' Network (SPAEN) and others.
- *Develop more flexible arrangements, to ensure that services are responsive, integrated and user-centred and identify and promote opportunities to involve disabled people in all decisions relating to services at all stages:*
 - Move to greater personalisation of provision to meet individual needs.
 - Undertake holistic assessment, which includes consideration of issues such as transport, housing, employment etc.
 - Ensure that provision is based upon a “social model” approach and meets the needs of disabled people.
 - Include disabled people in any decisions about their needs or care from the outset.
 - Recognise the key role of the individual service users in self-assessment (with independent advocacy, if required).
- *Develop the accessibility of service provision, and:*
 - Assess the accessibility of all services and information to disabled people.
 - Identify opportunities to improve provision and take steps to develop these improvements.
 - Ensure provision and support to particular groups of disabled people, as well as, where required, families and carers.
 - Address any problems identified.
 - Develop and disseminate good practice guidance relating to providing accessible services and information.
 - Ensure that key organisations in Scotland act as exemplars in their own practices.
- *Encourage organisations to put in place developments which are beyond the minimum requirements, through, for example:*
 - Improvements to access to the built environment.
 - Improved access to transport in advance of the legislation.
 - Development of local authority policies requiring that all new housing, including conversions and refurbishment, is built to agreed standards and that 10% is built to wheelchair accessible standards or is easily adaptable for wheelchair users.

- Promotion of barrier-free new build housing of all types.
- Development of the availability of a mix of types of appropriate housing.
- Identification of specific health-related initiatives for disabled people who experience ill-health.
- Development of work to ensure that local authorities take the initiative in Direct Payments development.
- Encouragement of organisations in Scotland to promote appropriate employment-related support and of employers to employ disabled people.
- Promotion of disabled people as potential employees and the employment of disabled people as a potential means of wealth creation.
- Adoption of a proactive approach to encouraging and empowering disabled people to seek and sustain employment.
- Encouragement of employers to adopt good practice in recruitment and working policies and procedures, including flexible employment options.
- Consideration of how to increase work-related opportunities.
- Promotion of Scotland as an accessible tourist destination.
- *Develop seamless provision and:*
 - Promote seamless movement between different services and parts of services.
 - Review provision at points of transition and identify gaps.
 - Ensure appropriate planning for points of transition.
 - Provide continuity and effective support at points of transition, and access to appropriate choices (including developing work to support transition from childhood to adulthood and school to further and higher education or training).
- *Use procurement processes to support and promote independent living and:*
 - Encourage consideration of disability and independent living issues in contracting and commissioning of services at a national and local level.
 - Promote disability equality and independent living in tender processes.
 - Develop relevant criteria for inclusion in tender documents, and evaluate tenders against these.

- Ensure that providers specify the ways in which they will promote independent living.
- Promote the employment of disabled people through the procurement process.
- *Develop incentives to encourage the development of appropriate actions, including through, for example:*
 - Establishing a “national accessible design award scheme” as proposed by the Scottish Parliament (2006a), and supporting local authorities to establish schemes locally.
 - Introducing incentives for transport developments in regional and local areas, as appropriate (with amendments to the Service Quality and Incentive Regime to include accessibility).
- *Identify and address any specific issues or barriers in service provision which have been highlighted, including through:*
 - Recognising the importance of housing repairs, improvements and adaptations in keeping people out of residential care, preventing admission to hospital and delaying discharge from hospital.
 - Ending the process of removing adaptations from housing.
 - Providing annual health checks and screening.
 - Developing improvements to the support to people with long term conditions.
 - Removing prescription charges for people with a chronic illness.
 - Considering the implications of continuing to means test provision of some community care services.
 - Developing innovative ways of providing for tasks not currently being undertaken, particularly those relevant to social care.
 - Developing good working conditions for Personal Assistants and considering other improvements to enable the employment of PAs.
 - Working with local colleges to take steps to increase the supply of Personal Assistants where necessary.
 - Taking steps to increase opportunities for disabled people to establish businesses and enter self-employment.
 - Identifying and considering ways in which the delivery of rehabilitation can promote independent living in Scotland, focusing upon employment issues within this,

taking account of the suggestions in PMSU report “Improving the Life Chances of Disabled People”.

- Implementing the recommendations detailed in the Scottish Parliament report about the establishment of a national framework for supported employment of disabled people.
- Developing more opportunities for work experience for young disabled people in education in Scotland and increasing opportunities for vocational training.
- Identifying ways of improving access to professional training for disabled people.
- Considering the role of community care contributions in acting as a disincentive to disabled people to accept higher paid work.

Funding and sustaining independent living

4.21 There is also a need to ensure that appropriate **funding and resources** are provided. Actions could include to:

- *Identify a common, evidence-based view of the costs and benefits of independent living in Scotland (developing the SQW work identified in Section 2) and:*
 - Promote the recognition of funding for independent living as a positive investment for the future.
 - Conduct a systematic, longitudinal cost-benefit analysis of the effect of independent living
 - Identify the economic and social costs of inaction and undertake more systematic exploration of the costs of “dependency” relative to independent living.
 - Use this information to guide decisions about expenditure.
- *Identify funding issues within existing key strategies and reports, and:*
 - Consider the implications of these recommendations.
 - Ensure the implementation of these recommendations.
- *Consider the distribution of current resources and:*
 - Review and examine the priorities for funding for services, changing the balance towards forms of provision which support independent living (e.g. through the Spending Review process).
 - Ensure issues relating to independent living are considered in the provision and use of mainstream

- funding of all services, and promote accessibility through regulatory and funding mechanisms.
- Accelerate funding to support specific improvements to accessibility (e.g. the station improvements with Network Rail).
 - Consider issues relating to provision for specific groups.
 - Consider the provision of ring-fenced funding, wherever possible.
 - Develop incentives linked to services which support independent living.
- *Identify and develop more flexible approaches to funding and commissioning services, and:*
 - Identify mechanisms for funding which enable people to move between areas without this impacting upon the services which they receive.
 - Adopt tender processes which include consideration of quality and equality, and enable competition by user-led disability organisations.
 - Provide greater clarity and direction on governance and funding arrangements for services.
 - Move towards greater pooling of budgets to provide community care and support services.
 - *Address some of the barriers to grant funding, and:*
 - Help to develop the capacity of user-led organisations to apply for and manage funding.
 - Help to develop the capacity of, and provide funding to user-led organisations to allow both service delivery and a contribution to policy development.
 - Develop and promote awareness of funding support.
 - *Address specific issues relating to resources in particular services, which might include, for example:*
 - Developing a consistent approach to charging for both employed and informal carers in leisure and transport provision.
 - Providing appropriate resources to enable disabled people to participate in public appointments.
 - Ensuring that access panels are resourced adequately throughout Scotland.
 - Identifying ways of addressing problems with access to housing finance for disabled people.
 - Considering improvements to funding for disabled students as part of the funding council review.

- *Ensure the provision of appropriate long term resources to support independent living, and:*
 - Identify potential central government funding to support key changes detailed which will contribute to independent living (e.g. in the establishment of a central development fund).
 - Identify appropriate means of passing some of the cost savings made as a result of independent living back to service providers.
 - Identify policy-specific funding sources for improvements to provision to disabled people in each of the policy and practice areas highlighted in this document by identifying this as a priority.
 - Identify opportunities in new funding for specific issues (e.g. homelessness) to address issues for disabled people.
 - Assess whether it is desirable to continue to treat Direct Payments as revenue neutral, and consider whether additional funding would lead to wider benefits.
 - Provide long term, sustainable resources to develop the capacity of user-led disabled people's organisations which work to the philosophy of independent living (including those working in specialist policy areas, such as transport).
 - Provide resources to develop disability equality training.
- *Ensure that funding provision supports the use of Direct Payments and:*
 - Identify specific funding to support an increased focus upon the implementation of Direct Payments.
 - Ensure that funding sources are sufficiently flexible to enable the use of Direct Payments.
 - Examine and develop appropriate and consistent systems of charging for personal support.
 - Consider the means of management and control of Direct Payments budgets and identify any improvements required.
 - Ensure that adequate funding is available to provide a living wage and proper annual increments for Personal Assistants.
 - Consider the best means of moving further towards individual budgets in Scotland.

TOWARDS A STRATEGY FOR INDEPENDENT LIVING IN SCOTLAND

4.22 Overall, it is suggested that all of these suggestions should help to inform the development of a strategy for independent living in Scotland in the future. They are intended not as a definitive and comprehensive range of actions, but as a starting point for further discussion, involving disabled people and other stakeholders (including organisations with expertise in specific policy areas). It is anticipated that the discussions will build upon, amend and develop these suggestions in the production of an independent living strategy for Scotland.

4.23 The final part of this report points forward briefly to the ways in which such a strategy might develop, both in terms of the issues which it might cover, and the process of development.

4.24 In terms of the issues which might be covered, it is suggested that the strategy should provide a clear national message, and identify the actions which are required at a national level. It should also identify some of the local developments which are seen to be required, whilst allowing local flexibility and decision making to enable the development of relevant work to reflect local community issues.

4.25 On the basis of the evidence which has been presented in this report, it is suggested that the strategy should be based upon a small number of key principles, which might include:

- Equality.
- Recognition of independent living as a human rights issue.
- Empowerment, choice, control and self-direction for disabled people.
- Mainstreaming (whilst recognising the need to identify and address disability issues).
- Personalisation and individualised provision.
- Inclusion and participation.
- The social model of disability.

4.26 It is suggested that the strategy could have, as its overall priorities, the achievement of independent living through appropriate provision in all of the areas highlighted in this report. These could

perhaps be summarised as 5S's²², based upon the broad key components of independent living outlined in Section 1, which could be defined as:

- Structure and society (described in this report as “the political, social and service structure”).
- Surroundings (described in this report as “the environment”).
- Support for individuals (described in this report as “personal support and services”).
- Social and economic opportunities (described in this report as “opportunities for economic and social participation”).
- Sustainability (described in this report as “funding and resources”).

4.27 Within each of these areas, the objectives which have been identified in each of the areas could form the basis of the more specific objectives of the strategy.

4.28 The actions suggested can then be considered further as the basis of an action plan. The locus of responsibility for each could be identified and the appropriate timescales, targets and measures detailed.

4.29 In terms of the structure for the strategy, it is suggested that this might include:

- The nature of independent living, the main definitions and the general context.
- The overall vision / message, key principles and objectives.
- Who the strategy is aimed at.
- The issues facing disabled people and the need for action.
- The priorities for change.
- The action plan, with timescales, milestones and targets.
- The means of implementation.
- Reviewing the strategy.

4.30 The strategy should include a process for incremental amendment as new developments take place and information becomes

²²The National Strategy to Address Domestic Abuse in Scotland, for example, identified 3P's.

available (or where there are any significant changes or developments which impact upon independent living).

4.31 It is also suggested that the strategy should acknowledge clearly the diversity of disabled people and their experiences. It will also be important to highlight the range of organisations and individuals who will require to participate in taking the strategy and actions forward, as well as the need for meaningful involvement by disabled people at all stages.

4.32 The strategy should also highlight the overlaps and links between different policy areas, stressing the need to ensure equality throughout all of these.

4.33 It is anticipated that the next stages in the development of the strategy will involve detailed consideration and discussion of the contents of this report, as well as the detailed nature and content of the strategy. As noted above, this will clearly need to involve disabled people and expert organisations across the policy areas identified, and it is likely that the actions which have been suggested will be amended and further actions identified during this process.

4.34 All of these considerations should enable the identification of an appropriate, evidence-based draft independent living strategy for Scotland in the future.

ANNEXES

ANNEX 1: METHODOLOGY

Reid Howie Associates was commissioned by the Disability Rights Commission (DRC) in late 2006 to carry out a policy scoping study on independent living in Scotland.

AIM OF THE STUDY

The overall aim of the policy scoping study was identified as being:

“to identify and critically examine the evidence of positive and negative policies which may impact on independent living”.

Within this, it was noted that the study should make recommendations on current opportunities and challenges in the implementation of independent living in Scotland, and help to identify a strategy for independent living policy implementation.

IDENTIFICATION OF KEY QUESTIONS

At the outset, a small number of key questions were identified which would form the basis of the review, as follows:

- What do disabled people want to achieve in terms of independent living, and what needs to be in place to allow them to do so (including the legal and policy framework)?
- What is in place currently and how does it match up to what is required (including the current situation for disabled people and their role in defining, managing and reviewing provision)?
- What are the enabling factors?
- What are the barriers and disabling factors?
- What changes are required?

THE METHODS USED

In order to answer these questions, it was recognised that a range of sources required to be explored, including the following:

- Legislation, national and local government policy (as well as that of other agencies including the NHS), and reviews of the provision of services.
- The views of disabled people in existing reports and materials (in terms of their aspirations and experiences of services).
- Statistics on a wide variety of issues, including provision to support independent living and the wider context of the experiences of disabled people.
- The view of stakeholders.
- The views of disabled people in Scotland.

Legislation, policy and service reviews

An extensive amount of material focusing on legislation, policy and service reviews was examined. This included material from the Scottish Executive and Parliament, from UK government departments and other material. There was found to be an extensive body of literature from Scotland, England and Wales (including material which had been prepared to support the development of strategies, as well as reviews of support provided to disabled people in relation to the range of policy areas covered in the report). There was also found to be a good deal of information available on Direct Payments specifically (aimed both at end users and service providers) both from published sources and from material supplied by local authorities and others for this research. All of this material was examined and summarised²³.

Although the main focus of the research was on Scotland, much of the legislative structure is common (for example, the DDA, benefits and employment). Although preference was given to Scottish material (where this was identified), it was also seen to be important to include material relating to England and Wales, or the UK as a whole.

Many of the documents examined were identified through departmental web sites, although some were also provided by other participants in the research (including members of the Steering Group and a wide range of voluntary organisations, local authorities and NHS bodies). Searches

²³ It should be noted that the language used in presenting this material is often similar to the language used in the original material, whilst not necessarily being presented as a verbatim quote. This is considered important in order not to change the meaning of the material. The sources of the information are, however, acknowledged.

were also undertaken using the British Library “Inside” service and the catalogue of the National Library of Scotland.

It was also recognised that local authorities and NHS bodies were likely to have a range of local material relating to issues pertinent to independent living, which was either not widely available, or which may be contained within committee papers. It was also clear that local authorities often produce work for their own use, which may not be “published” but may be in the public domain.

In order to identify and include this material, key public bodies were asked to identify material about the aspirations and experiences of disabled people, and to provide copies of any policy or service review material available. Although some bodies chose to view this as a freedom of information request (and one local authority declined to make provision as a result of this) this generated a substantial amount of valuable additional material.

Published material - the views and experiences of disabled people

The identification of published material relating to the views and experiences of disabled people was undertaken using the combination of sources highlighted above, as well as the websites and newsletters of agencies and organisations of and for disabled people. A large number of national and local disability organisations were also contacted and asked to send any relevant material.

Statistical material

Some statistical material was also examined, in order to provide a basic understanding of key issues relating to levels of demand and provision, and this included:

- Consideration of existing statistics on disability in Scotland to try to assess the potential “target market” for independent living.
- Consideration of the implications of this for provision.
- Identification of any key gaps in provision.

Although this is presented within the body of the report, it was not intended that this should comprise an examination of supply and demand, but should form part of an overall consideration of any clear gaps in provision and suggestions for development. As such, any

relevant material has been included in the appropriate sections of the report.

Discussions and postal survey

In addition to the desk research, it was considered important to carry out a series of discussions with a range of stakeholders. Although it was recognised that this report would be largely desk-based, and would be a precursor to wider discussion as a strategy develops, it was also recognised that some preliminary discussions would be helpful. These were undertaken in order to set the work in its wider context, and to address any potential gaps in published material.

A small number of groups of disabled people were convened with the assistance of Steering Group members and local forums / networks. Three two-hour discussions were held (in Glasgow, Edinburgh and Fife) with around 10 participants in each. The discussions were wide ranging on the subject of independent living, and were designed to ensure that the emerging material from the other strands of the study reflected disabled people's views of the key issues in independent living. The discussions were taped, and the issues emerging have been included within this report.

In addition, when the request for information was circulated to national and local organisations of and for disabled people, they were also asked to make a short pro forma available to disabled people who may wish to contribute their views to the research. This was also made available via RHA's website, and although it was not anticipated that there would be a large response, it was considered important to ensure that anyone who wished to raise an issue was able to do so.

A total of 46 responses were received (although this represented a higher actual number of people, as several of the responses were from organisations). It should be stressed, however, that this strand of the process was not intended to comprise large-scale, representative research, but to provide a further opportunity for any key issues to be identified. This material was analysed qualitatively, and has been included in the report at appropriate points (although, as with other material, it has not always been identified separately).

OVERVIEW

Taken together, the output of all of these strands has formed the basis of this report, providing detailed evidence to help to address the key questions which were identified at the start. The material which has been presented has helped to identify: some of the requirements of independent living; the developments which have been undertaken; the barriers preventing independent living; and the changes and developments which are seen to be required.

The report has considered:

- The relevant definitions of independent living and the social model of disability, as well as the aspirations of disabled people and the requirements of independent living (Section 1).
- The current legislative and policy framework, and key ongoing developments (Section 2).
- The level of knowledge and awareness of, and attitudes to disabled people, as well as the adequacy of current implementation and barriers (Section 3).
- The changes which may be required to address these barriers (Section 4).

The report has also considered the need for a strategic vision, targets and milestones, and has suggested some of the key objectives and actions.

All of this material can form the basis of widespread discussion of the issues and suggestions made amongst disabled people. This, in turn, can build a strategy for independent living in Scotland, which can form the basis of future action to address the issues identified.

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ANNEX 3: GLOSSARY OF ABBREVIATIONS

BSL	British Sign Language
CEHR	Commission for Equality and Human Rights
CHP	Community Health Partnership
CIL	Centre for Independent (or Inclusive or Integrated) Living
DRC	Disability Rights Commission
DDA	Disability Discrimination Act
DPHS	Disabled Persons Housing Service
DPTAC	Disabled Persons Transport Advisory Committee
DWP	Department for Work and Pensions
FIDN	Fife Independent Disability Network
ILF	Independent Living Fund
LGBT	Lesbian, Gay, Bisexual and Transgender
MACS	Mobility and Access Committee for Scotland
NCIL	National Centre for Independent Living
NEET	Not in education, employment or training
NUJS	National Union of Journalists Scotland
ODI	Office for Disability Issues
Ofcom	Office of Communications
PMSU	Prime Minister's Strategy Unit
RNIB	Royal National Institute of the Blind
RNID	Royal National Institute for Deaf People
SAIF	Scottish Accessible Information Forum
SBSA	Scottish Building Standards Agency
SCVO	Scottish Council for Voluntary Organisations
SDEF	Scottish Disability Equality Forum
SUSE	Scottish Union for Supported Employment
VDS	Volunteer Development Scotland