



## A Scoping Study on the Needs of, and Services to, Younger Disabled People Including Those With Early Onset Dementia, in Scotland

**A SCOPING STUDY ON THE NEEDS OF, AND  
SERVICES TO, YOUNGER DISABLED PEOPLE  
INCLUDING THOSE WITH EARLY ONSET  
DEMENTIA IN SCOTLAND**

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## **EXECUTIVE SUMMARY**

### **AIMS AND METHODS**

The main aim of this six-month scoping study was to review research and related evidence about the needs of, and services to, disabled people aged 16-64 in Scotland, including people with early onset dementia. Other important objectives were to identify the volume of evidence on different topics, gaps in current knowledge, relevant research in progress and key emerging issues, both overall and those affecting particular groups of disabled people.

Our approach was broadly informed by the social model of disability. However, this report necessarily reflects the fact that much disability research is impairment specific. In addition, in line with the research specification, the study does not include people with learning disabilities or mental distress.

The research was conducted using a six part framework for scoping studies, comprising:

Stage 1: Identifying the research questions

Stage 2: Identifying relevant studies

Stage 3: Study selection

Stage 4: Charting the data

Stage 5: Collating, summarising and reporting the results.

Stage 6: Consulting with key stakeholders.

(Arksey and O'Malley 2005).

The evidence scoped covered the 10 year period up to December 2004 with the main focus on Scottish publications. A systematic search strategy was used on all relevant electronic databases, national statistics were examined and approaches made to academic institutions, specialist organisations, voluntary agencies and organisations of disabled people, requesting them to alert us to relevant material. A Microsoft Access database was designed to manage material and catalogue references. Most items related to more than one topic so there is considerable overlap between the studies scoped in the various sections.

The Scottish Disability Equality Forum (SDEF), an umbrella body representing 140 organisations, was consulted at various stages of the study – when drawing up the research proposal, when searching for relevant material and at the draft reporting stage.

The main limitations of the study lie in its short timescale and restricted budget. This has meant we have been unable to include unpublished work, visit specialist libraries nor hand search journals. Thus, the material presented in this report is not comprehensive.

### **MAIN FINDINGS**

#### **Equality and Diversity**

Thirty-two publications relating to equality and diversity were identified, 23 of which included disabled people's perspectives. Research has shown a high level of hate crime against disabled people in Scotland, although market research about public awareness and attitudes towards disabled people has elicited mainly positive responses. There has been

relatively little research about the needs of disabled people from Black and minority ethnic groups in Scotland, with studies tending to be impairment or location specific. Nevertheless there are some recurring themes - a lack of awareness of services, often linked to poor information provision, cultural insensitivity within services, discrimination within the labour market and the benefits system, and a continuing acceptance of certain stereotypes about Black and minority ethnic families.

Little research has been carried out about gender and disability in Scotland. We were unable to find any published research about lesbian, gay, bisexual and transgender people with physical/ sensory impairments in Scotland. An English study exploring the experiences of disabled people with multiple identities reported mostly positive findings but, overall, the evidence suggests that diversity is not always seen in this light. Overall there is a need for greater emphasis on all disabled people being treated with courtesy, dignity and respect.

### **Needs Assessment**

Twenty-eight publications are included in this section, although not all have needs assessment as their main focus. Sixteen include users' perspectives. The research tends to be either impairment specific or to look at assessment for particular services. No statistics are kept about unmet need yet a meaningful strategy to record it is essential in order to satisfy the needs of forward service planning. Needs are often discussed in terms of the services deemed necessary to meet them rather than in a wider 'needs-led' context. Overall, disabled people are portrayed as having needs rather than rights or entitlements.

Research in England has suggested that disabled people find community care assessments 'confusing and fragmentary' and often irrelevant to their real concerns. Differences between users' and professionals' priorities are a recurring theme, for example, social workers may fail to grasp the mutuality of many caring relationships. Professional decisions about assessment are often based on service criteria and perceived risk, both framed more narrowly than disabled people may see them. Taken as a whole, the research suggests that disabled people have a low level of involvement in the assessment process.

Needs assessment is subject to geographic variation, with local authorities, and sometimes local teams within authorities, interpreting central guidance differently. Arrangements for assessing the needs of people with sensory impairment in Scotland are described as ad hoc and subject to delay. The benefits of a holistic, multi-disciplinary approach are emphasised.

### **Transition to Adulthood**

Fourteen publications relating to transition to adulthood were found, 10 of which report young people's views. There is little research specific to Scotland, although there are two recent reviews of the literature, one relating to Scotland. The main message from this research concerns the difficulties surrounding transition planning, both in terms of involving young disabled people in the process and ensuring that plans made are carried through. While most young people see leisure and friendships as important elements of moving towards adulthood, as well as finding opportunities for study and work, professionals may tend to see transition more narrowly, in terms of moving young people out of children's services and into adult provision. Poor co-ordination between children's and adult health and

social care services has been reported frequently although there are increasing examples of good practice projects aiming to ease the transition.

Young disabled people face barriers in their everyday lives, in the form of inaccessible transport, the built environment, the impact of segregated education and the negative attitudes of others. Lack of appropriate support to overcome these obstacles can leave young people excluded from mainstream youth activities and culture.

## **Education**

There are 22 publications on this topic, 14 including disabled people's views. There is a relatively high proportion of Scottish research. The research identifies various structural and institutional barriers to disabled people accessing education and achieving their full potential. Such barriers may be viewed by professionals in terms of individual, even medical, needs. Low expectations of disabled people among service providers, particularly those involved in transition planning and careers guidance can hold people back. The concept of inclusion may be misinterpreted as meaning that everyone should be treated in the same way, rather than incorporating disabled people's needs in all policies and procedures. However, more recent research points to progress in making appropriate provision, likely to be further improved by recent legislative changes.

## **Employment**

We identified 39 publications about employment, including several Scottish specific studies. Twenty included disabled people's views. A review of the evidence base in this area has just been published by the Scottish Executive (Riddell et al 2005). It is well known that disabled people are poorly represented in the labour market and, even when employed, can be subject to financial exclusion and disadvantage. There is still much work to be done to understand and respond to disabled workers' needs: many want more structured, formalised support. The benefits of supported employment, as perceived by disabled people, service providers and employers, are well documented. Supported employment works well for some people with complex needs but funding arrangements are generally short term and insecure.

There is evidence that the New Deal for Disabled People is failing to address underlying barriers to employment linked to exclusionary market and welfare structures. There is a lack of suitable jobs for disabled people, with many fearing they will not be able to return to Incapacity Benefit if they stop working. It is too soon to assess the impact of the new provisions of the Disability Discrimination Act (DDA) 1995 affecting employers. However research suggests that the government could do more to counter misunderstandings held by employers about the DDA.



## **Benefits**

Thirty publications relating to benefits were found, 17 including disabled people's perspectives. Much of the research relates to the UK as a whole, reflecting the fact that social security is not a devolved matter.

There are complex links between impairment, socio-economic status, employment and benefit receipt. Wide variation exists in disabled people's financial situations depending on what benefits they know of, apply for and receive. Households with a disabled member have incomes 20-30% below that of other households. Taking account of the extra costs they face, half of all disabled people in the UK have incomes half that of the general population mean, usually taken as an indicator of poverty.

Access to financial resources is a major factor in disabled people feeling able to overcome the disadvantages they face yet research shows that current benefit rates for disabled people are inadequate to meet their needs. A complex system, inflexible rules and poorly branded benefits create difficulties for many, especially those from Black and minority ethnic backgrounds. Obtaining independent financial advice has been a turning point for some disabled people. Recent research has focused on measures to help disabled people off benefits and into work.

## **Housing**

There are 26 publications in this section, many of them specific to Scotland, with 13 presenting disabled people's views. A good deal of detailed information exists about tenure, technology, disabled people's aspirations, affordability and good practice. However, the quality of information held by local authorities about disabled people's housing needs is said to be poor, rarely taking account of their views. Little is known about the needs of people in rural areas.

Access to suitable housing is key to establishing independence, although market driven and financial barriers can get in the way. Disabled people are twice as likely as others to live in the social rented sector. Research points to a limited level of user choice and understanding about housing support arrangements.

## **Transport**

This was the topic where least evidence was found - only 8 publications, although this includes 2 Scottish reviews. Six include disabled people's perspectives. The apparent paucity of research on this topic was identified as a concern in our consultation with SDEF.

National statistics show that disabled people are less likely than others to hold a full driving license and households with a disabled member are less likely than others to have access to a car. Forty-seven per cent of disabled people are unable to use their local bus service. Uncertainty about the reliability and accessibility of transport can be a source of stress and deters some people from travelling. Disabled people have reported unhelpful attitudes among service providers. There is a need for an integrated and well co-ordinated public transport

policy both nationally and locally. There have been improvements in accessibility recently although, overall, change remains slow and patchy, with geographic variation reported across Scotland.

### **Goods, facilities and services**

Eighteen publications were identified on this topic, although few of them are specific to Scotland. Twelve include disabled people's views and there is some focus on young people's experiences.

Research in 2002 found that where organisations had made 'reasonable adjustments' to their services (as required by the DDA), this was usually in the form of physical adaptations, providers wrongly believing that their services were then accessible to everyone. Few had detailed knowledge or understanding of the DDA and the overall response to the legislation by service providers has been described as disappointing. One in five disabled people experience difficulties accessing goods, facilities and services. These include staff attitudes, the nature of the built environment, poor information provision, unhelpful presentation of goods and failure to use available technologies.

### **Social care - needs and services**

Fifty-seven publications fall into this category, 28 reporting users' views. Most focus on particular groups of disabled people or specific services: the most recent overview of social care services to disabled people in Scotland was published nearly 10 years ago.

Twenty-four per cent of disabled adults aged 16-54, and 19% of those aged 55-64, require regular assistance. Research in Scotland has identified a lack of clarity about the objectives of care management although practitioners report more success in supporting disabled people at home than other user groups, because a range of funding sources is available.

People consistently report that being able to exercise choice and control in their support arrangements is of paramount importance. Organisational culture and staff attitudes can militate against this. Although take-up of direct payments has been slow in Scotland, a wide range of benefits is consistently reported. Disabled people want flexible services, responsive to individual needs and preferences and able to offer a range of practical, emotional and moral support. Research points to certain gaps in services and a shortage of provision for particular groups, including people with early onset dementia who are often inappropriately included in services for older people with dementia. Here, staff role and attitudes are crucial, a holistic approach is required and more evidence based training is needed, a point endorsed in our consultation with SDEF. There is a great deal of information available from both statutory and voluntary bodies and there is an identifiable demand for that information but what is absent is the mechanism to bring these two together in an easy and efficient way.

### **Health care - needs and services**

This topic yielded 46 publications, including 32 specific to Scotland. Twenty-five publications report users' views.

Most of the research is based on a medical model of disability although the relevance of the social model is pointed out by some writers. The importance of accessible environments and inclusive attitudes and practices, if disabled people are to benefit from health care provision, is stressed. A number of studies examine rehabilitation services, with some pointers to good practice identified, for example, involving people with communication impairments in setting rehabilitation goals and employing a writer-in-residence within a rehab unit. However, it is also suggested that ‘younger’ disabled people living in nursing homes have few opportunities for review and rehabilitation, while rehab services for amputees are under-used. There is a need to make greater provision for younger stroke patients.

Research repeatedly underlines the importance of collaboration and joint working between health care professionals working in different areas and between health workers and colleagues in other disciplines. There is growing evidence about the health care needs of people with profound multiple impairments and those with early onset dementia.

### **Equipment and adaptations**

We identified 17 publications in this area, 11 containing users’ views. Long waiting lists and delays in providing equipment and particularly adaptations are frequently reported. These are attributed by more than one source to problems associated with authorisation of funding and a lack of delegated decision-making. Again, there is geographic variation across Scotland. There have been significant developments in policy and practice over the last decade, reflecting underlying changes in thinking about the purpose of providing equipment and adaptations to disabled people. The most recent publications focus on joined up, person centred services, aiming to promote equality and social justice. Proposals are made for future developments in mainstreaming provision and more inclusive design.

### **Technology and communication**

Fifteen publications fall into this topic, 8 including a user perspective. Recent research highlights the huge potential of cyberspace for disabled people but the financial costs of buying a computer and the associated technologies that may be required prevent many disabled people from going on-line. A number of studies explore the benefits and limitations of both low- and high-tech communication aids. Speech and language therapists have wide ranging skills in direct communication work with disabled people but it is suggested that many are less than comfortable with the technical aspects of equipment.

### **Families and carers**

There are 32 publications on this topic, most small-scale, qualitative and impairment group specific. Carers’ views are given in 12 studies, disabled people’s in 8. These studies should be seen in the context of the wider literature on caring, which is a contested field. Commentators have challenged the representation of caring as a ‘burden’ and the usefulness of the concept ‘young carers’, while also stressing the need to recognise the interdependence within many caring relationships.

The studies scoped suggest that, overall, researchers have moved on in their thinking, with many focusing on support needs, rather than ‘burden’ and several including disabled people’s perspectives. Carers want more accessible information, fuller assessments of their own needs, short breaks and counselling. The timing of support offered to carers is crucial, as is a partnership approach. As some studies illustrate, disabled people’s relatives are not necessarily their carers, nor do all families show ‘caring’ attitudes towards their disabled members. It is reported that children of people with early onset dementia may feel shame and embarrassment, while some disabled women are subject to violence and abuse at the hands of their partners.

## **Unmet need**

Forty-five publications contain information about unmet need but in many cases this is not their main focus: 23 include disabled people’s views. There are no national statistics about unmet need. Unmet need is approached in various ways - in terms of structural or attitudinal barriers, impairment group, type of unmet need, shortage of particular services and perceived shortcomings of specific provision. Barriers identified include inaccessible transport, housing, education, retail services, the built environment and low incomes. Specific groups identified as having significant unmet needs include people with early onset dementia, those with profound multiple impairment and individuals with sensory impairment. Services in short supply are said to include clinical psychology and legal advice and information. Some good practice is identified, aimed at overcoming the barriers contributing to unmet need.

## **CONCLUSIONS**

### **Summary of volume and nature of evidence**

The total number of items scoped was 223, the majority being research studies. Most evidence relates to the statutory sector, with surprisingly little about the voluntary sector and less about private provision. Just over half the publications were exclusively about Scotland.

The study included examination of all relevant statistical sources. Due to differences in the terms and definitions used - some asking questions about physical disability, others about mental disability, impairment, illness and other health issues - it is not always possible to isolate data relating to people with physical/ sensory impairment. Similarly, degree of impairment is not always evident in statistics. The Scottish Household Survey should continue to provide valuable time series data on prevalence and use of services in the future. More in-depth analysis linked to degree of impairment is available from the Disability Surveys for Great Britain.

### **Key emerging issues**

A striking feature of much research and related evidence is the absence of an explicit theoretical framework. Much is impairment specific, implying a medical model of disability, with a focus on individuals’ care needs. Other work conceptualises the challenges disabled people face in terms of barriers. Some studies oscillate between different perspectives.

Barriers to meeting disabled people's needs /rights and providing effective services can be identified at various levels. Examples of structural barriers include inaccessible housing, transport and aspects of the built environment. There are many policy barriers, such as segregated schooling and lack of effective inclusion policies within further and higher education. Several studies illustrate the 'knock-on' effect which barriers in one area can have on others; for example, transport related exclusion impacts on people's ability to work and to access leisure facilities. Problems at policy level can cause barriers within services and thus, at practice level. The fact that much research relates to particular services reflects the patchy and piecemeal nature of current provision, with geographic variation reported across Scotland, for example, relating to care management, direct payments and provision of equipment and adaptations. Delays in provision and shortages of specific services are reported. Barriers at cultural or attitudinal level are also discussed. These include an entrenched culture in some organisations which can make professionals reluctant to share power, and disrespectful attitudes towards disabled people on the part of service providers and the public more largely.

Disabled people are a heterogeneous group like any other and therefore there is no 'one' user view but rather a range of opinions, some of which may conflict. It is important to try to avoid over generalisation or over simplification when reporting disabled people's views.

There is limited discussion within Scottish research about disabled people's views across the board. There is evidence of people being consulted about individual studies or specific services. It appears there is great scope for wider and more active involvement of disabled people in setting research, policy and practice agendas.

At the individual level, disabled people frequently report a lack of accessible information and sometimes, in relation to finances and welfare benefits, confusion about how the system works and their own entitlements. Experiences of assessment are not good overall. Disabled people's views and priorities may differ from those of professionals who may tend to perceive the latter as service users or social work clients rather than seeing their lives and identities in the round.

### **People with early onset dementia**

Research about people with early onset dementia in the UK is limited, and particularly so in Scotland, with much information being anecdotal. Thirty publications were included here. Studies about people with dementia often fail to consider the needs of those with early onset dementia. Both specialist and generic services have an important part to play. The aim of much research is to improve services, for example by identifying the elements of well co-ordinated care addressing primary need. The literature on services to this group should be seen in the wider context of services for people with dementia, which are generally marginalised and under funded.

### **People with sensory impairment**

While there is relatively good information about services to people with sensory impairment and about Deaf people in Scotland, less is known about those with visual impairment and deaf-blind people. Indeed, data about the numbers and needs of the deafblind community is

not complete. There is ongoing debate about various aspects of provision to people with sensory impairment in Scotland – whether community care teams should be impairment specific for example, and the value of contracting out services to the voluntary sector. People with sensory impairment face additional expenditure to meet their daily needs and can experience considerable isolation and prejudice. The Scottish Executive (2004a) has recently issued an action plan for services in this area.

### **People with profound multiple impairment (PMI)**

Recent years have seen a remarkable change in the nature and pattern of service provision for this group yet significant challenges remain in meeting their needs. People with PMI are at risk of being excluded in many areas of their lives: thus, there is a need for staff to be very proactive in their approach. Evidence exists about many aspects of the experiences of people with PMI and how best to support them: the need now is to incorporate that evidence in staff training so that it can be better translated into practice. There is growing awareness of the mental health needs of this group, although more work requires to be done in this area.

### **Good practice**

Less information than expected was identified about good practice. This does not mean it does not exist but, rather, that it is not being documented or evaluated. Innovative, user led work within voluntary agencies and organisations of disabled people may not be widely publicised. There is a need for an easy mechanism to share good practice on a regular and informal basis. However, a number of good practice projects and initiatives were identified in Scotland. Many studies discuss the values and principles underlying good practice as well as some of the necessary practical conditions. These include

- putting disabled people at the centre of policy design and service delivery
- adequate, timely and coordinated interventions
- accountability to disabled people
- cost effectiveness
- joined up working
- accessible information provision
- the ability to make choices and feel in control
- age appropriate services
- a multi-disciplinary, holistic approach.

### **Gaps in knowledge**

Finally, the need for further research was identified in relation to most topics. In some cases this is because little previous work has been done, in others, there is a need to examine the impact of new policies or legislation or to evaluate new initiatives. The importance of involving disabled people in planning and conducting studies, ‘mainstreaming’ disability issues within research where appropriate, and giving feedback to service users who have participated in research, is emphasised.

## **PART 1: AIMS AND METHODS**

### **INTRODUCTION**

1.1 In September 2004, the Analytical Services Division of the Scottish Executive Health Department commissioned the Department of Applied Social Science at the University of Stirling to undertake a scoping study on the needs of, and services to, younger disabled people, including those with early onset dementia. This report presents the main findings of the research 6 months later, drawing on a total of 223 research studies and related evidence.

1.2 The report is divided into three parts. Part One sets out the aims and methods of the study, including a note on its limitations. Part Two presents the main findings of the research and is divided into 15 sections, each dealing with a substantive topic. Part Three presents and discusses the study's conclusions, including an overview of the amount and distribution of all the material reviewed in the study and a commentary on national statistics and surveys.

### **NOTE ON TERMINOLOGY**

1.3 Our approach to this study has been broadly informed by the social model of disability (Oliver 1990, Campbell and Oliver 1996, Thomas 2004) which draws an important distinction between 'impairment' and 'disability'. The former refers to loss or limitation of a person's physical, sensory or cognitive ability or function. In contrast, 'disability' is understood as 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities' (UPIAS, 1976, 3-4). For this reason, we refer to 'disabled people' rather than 'people with disabilities'; the former term includes people with early onset dementia (whether or not they have physical impairment). At the same time, in line with the tender document issued by the Scottish Executive, attention has been given to evidence relating to people with particular impairments who may face specific barriers or have particular needs, such as people with sensory impairment and those with profound and multiple impairments.

1.4 Presentation of the findings inevitably reflects the fact that much disability research is impairment specific. However, as set out by the Scottish Executive specification, the study does not extend to people with learning disabilities or mental distress who do not have physical impairment.

### **AIMS AND OBJECTIVES**

1.5 The main aim of the study is to identify available evidence about the needs of disabled adults, aged 16 - 64 including people with early onset dementia, and the ways in which these needs are met. Specific objectives are as follows:

1. to identify and describe from the existing research what is known about the following topics:

- assessment
  - needs
  - unmet needs
  - social care
  - health service provision
  - housing and housing support
  - aids and adaptations
  - informal support
  - benefits
  - transport
  - technology
  - education
  - disabled people's views and experiences of need and service provision
  - good, innovative and user-focused practice;
2. to indicate the volume of relevant evidence on different aspects of the topic and identify any gaps in the evidence base;
  3. to identify current statistical information available on different aspects of the topic and provide a narrative on the trends, implications and limitations of the statistics;
  4. to map out any relevant research currently underway which will add to the evidence base;
  5. to identify key emerging issues relating to disabled people overall;
  6. to identify key emerging issues relating to particular groups, such as people in minority ethnic groups, people with multiple impairments, people with specific impairments and people with multiple identities
  7. to identify evidence on service users' perspectives and roles in decision making.

## **METHODS**

1.6 There has been relatively little discussion of the scoping study as a methodology in its own right, nor have many researchers who have conducted scoping studies given detailed accounts of the process (Arksey and O'Malley 2005). More has been written about narrative and systematic reviews (eg: Cochrane Collaboration 2003, Davies and Crombie 2003). Scoping studies differ from these in several ways. First, scoping studies are unlikely to address very specific research questions; secondly, they aim to achieve breadth rather than depth of coverage; thirdly, they are not based on any perceived hierarchy of research methods, in the way that systematic reviews generally favour randomised control trials; lastly, scoping studies do not attempt to assess the quality of the research reviewed (Arksey and O'Malley 2005). However, these features do not mean that scoping studies should be seen as 'second' or 'third best' to systematic and narrative reviews. They offer the advantage of wider coverage and must still be methodologically rigorous and transparent.



The method used in this study comprised a six part framework, as outlined by Arksey and O'Malley (2005), namely:

Stage 1: Identifying the research questions

Stage 2: Identifying relevant studies

Stage 3: Study selection

Stage 4: Charting the data

Stage 5: Collating, summarising and reporting the results.

Stage 6: Consulting with key stakeholders.

Each stage is described in more detail below.

### **Stage 1: Identifying the research questions**

1.7 The aims and objectives of the study are identified above.

### **Stage 2: Identifying relevant studies**

1.8 The study reviewed published and on-going research and related evidence, such as official statistics, about the needs of, and services to, disabled adults aged 16 - 64, including people with early onset dementia, relating to the period 1995-2005. Key parameters for the study were set down in the research specification which stated the period to be reviewed, the different groups of disabled people to be included, and the range of equality issues and service sectors to be taken into account. The focus of the study is firmly on Scotland, although this includes UK studies with a Scottish component. Given the extensive and disparate range of objectives identified for this study, and the various different groups to be included, coupled with the short timescale, it would have been unrealistic to attempt to identify and review material from elsewhere. Nor is there any reason to suppose that the needs of disabled people in Scotland differ from those of disabled people elsewhere. However, where there was relatively little Scottish research, we have included some studies conducted elsewhere in the UK. We have also drawn on findings about good and innovative practice from elsewhere in the UK and internationally.

1.9 This short study had a long list of objectives, and many of the topics investigated are substantial areas in their own right. Thus the first task was to identify any recent reviews of the literature (eg: Reid Howie Associates (1999, 2003) on transport and disabled people; Stalker (2002) and SCIE (2004) on transition). It was then possible to focus mainly on identifying research published since these reviews, thus avoiding unnecessary duplication.

### **Sourcing references**

1.10 In consultation with the University of Stirling Librarian for the Social Sciences, a systematic search strategy was developed for identifying relevant studies. The following electronic databases were searched for relevant material:

- *Sociological Abstracts and Social Services Abstracts, Web of Knowledge and IBIS (International Bibliography of the Social Sciences), Social Science Citation Index*

(which includes *ReSearch Web*), *Caredata* and *Idox* (Planning Exchange). The Joseph Rowntree Foundation, the Scottish Executive and The Community Fund have been major funders of disability research in Scotland in recent years: their websites were searched for references, as was the Department for Work and Pensions (DWP) website for research relating to benefits and employment.

- *Non peer-reviewed journals* which feature policy and practice focused articles on disability and/or dementia services, such as *Community Care and Dementia Care*, were also searched.
- The *Current Awareness Service* produced by the Dementia Services Development Centre at the University of Stirling was scrutinised for relevant references.
- *Research in progress*: *HERO* website was searched for links to resources for information about current research activities across the UK, as was the Regard database which identifies current research funded by the ESRC. Contact was made with university departments and experts in the field to ask if they would be willing to share findings from work in progress.
- *Specialist organisations*: To identify work relating to particular groups of disabled people, contact was made with agencies representing minority group interests; for example, the Equality Network for research on lesbian, gay, bisexual and transgender (LGBT) disabled people, and the Glasgow Anti-Racist Alliance for work relating to disabled people in Black and minority ethnic communities.
- *National statistics*: The review of current statistical information included all relevant sources, including the 2001 Census, the Scottish Household Survey, The Scottish House Conditions Survey, the Scottish Health Survey, and the Social Focus on Disability (Scottish Executive 2004b) as well as statistics routinely collected by the Scottish Executive.

## Search terms

1.11 The core keywords used to search were

*assessment or need or support*

AND

*disability OR dementia*

AND

*Scotland OR Scottish.*

Searches for each topic were then refined by adding further keywords such as

*education*

or

*housing.*

1.12 In order to identify all relevant literature in the search, the keywords were truncated (with \*) thus ensuring all appropriate references were identified. For example, *disab\** finds literature relating to disabilities, disability and disabled.

1.13 Conducting searches for literature about early onset dementia is problematic due to definitional issues which reflect to an extent the specialist concern and the generic concern to promote the wellbeing and quality care of all people with dementia. There is no clear consensus in the literature about the use of the term ‘early onset dementia’ (Beattie et al 2002). For example, the word ‘early’ is used to describe ‘early onset dementia’ (that is, those who develop dementia before they are 65) while stage theories of dementia use the term ‘early stage dementia’ to describe those over 65 with mild cognitive impairment.

### **Stage 3: Study selection**

1.14 The abstracts and/or information about each study were scrutinised to ensure their fit with the inclusion criteria. The full text was then obtained for all works to be included, and in any cases of doubt. Here, a final decision was made after sight of the full text and, where necessary, consultation with other members of the research team.

1.15 The tender document specified that research relating to people with physical impairment and learning disabilities should be included. However, initial searches revealed that many studies about people with learning disabilities do not differentiate between those with or without physical impairments, or even report if any of the sample had a physical impairment. Even if people were identified in this way, the study’s short timetable precluded searching all the literature on people with learning disabilities. It was therefore agreed with the study commissioners to focus on work relating to people with ‘profound’ and multiple impairments, i.e.: those with physical impairments and a very high level of cognitive impairment, who are virtually always identified as a discreet group and whose needs are often said to be poorly understood and met.

1.16 In order to keep the study manageable and focused on its primary aims and objectives, it was decided to exclude medical research and studies only relating to people with chronic medical conditions or illnesses. Similarly, in relation to housing, transport and services for people with sensory impairment, ‘technical’ research about aspects of design was excluded.

### **Stage 4: Charting the data**

1.17 The Microsoft Access software package was used to manage material and catalogue references selected at Stage 3. The database contains full citation details for data sources together with ‘review’ information about each, recorded on a structured proforma (see Appendix 1). This allows references to be readily accessed by topic. The proforma recorded:

- publication details
- topic (as defined by author)

- topic (scoping study categories)
- study population (as defined by author)
- type of study
- sample details
- key findings
- geographic coverage
- service sector
- inclusion of user perspective (yes/no)
- good practice example (yes/no)

1.18 Before completing this stage of the process, it was possible to quantify the number of references collected for each topic and thus identify areas about which there was less material, such as aids and adaptations, technology, gender, poverty and disabled parents. Efforts were made to identify further material in these areas, for example by contacting academics and policy makers working in these fields. This exercise was relatively successful. However, for practical reasons, a date was set, in mid-December 2004, after which no additional searches were carried out.

### **Stage 5: Collating, summarising and reporting the results**

1.19 The data were collated, and are presented, in two ways – numerically and thematically. A manual count was performed of the number of studies/ evidence relating to each topic in terms of publication format, type of evidence, geographical location and inclusion of users’ perspectives. The main findings within each topic were carefully perused, brought together thematically and summarised: they are presented in 15 sections in Part Two. It should be stressed that most publications were classified as relating to more than one topic with a significant proportion straddling several topics: thus, there is a good deal of overlap in the studies scoped and discussed in the various sections. Part Three presents an overview of the volume of material of different types as well as drawing out wider conclusions and implications for further research.

### **Stage 6: Consultation exercise**

1.20 It is recognised that systematic reviews are strengthened where they involve some contribution from service users and providers (Oliver 2001). Although presented as an ‘optional extra’, Arksey and O’Malley (2005) stress the benefits of including an element of consultation within a scoping study. An approach was made to the Scottish Disability Equality Forum (SDEF) inviting them to contribute to this research. SDEF is an umbrella organisation representing 140 disability organisations across Scotland. Its main aim is to help ‘ensure the voices of disabled people are heard in the new Scotland’ (see [www.sdef.org.uk](http://www.sdef.org.uk)). The researchers met with representatives of SDEF at an early stage of the study and asked them to identify

- any published research they had carried out, or work in progress, relating to disability and/or early onset dementia
- any grey literature they were aware of

- any published examples of good / innovative practice, in their member agencies or beyond.

1.21 SDEF circulated a letter to members asking for suggestions. This was a useful exercise which identified some new research. A letter received from one of SDEF's member organisations is reproduced in Appendix 2. Following submission of the draft final report to the Executive, a summary was circulated to SDEF's member organisations. They were asked to comment on

- the implications of emerging findings
- gaps in the evidence base, especially in relation to people with complex or particular needs
- the issues SDEF would identify as priorities for future research, within the broad area covered by this study.

1.22 Their response is incorporated in this report.

1.23 In addition, during Stage 2 of the study, an approach was made to a wide range of organisations of disabled people and voluntary organisations asking them to help identify relevant studies and good practice initiatives, as outlined above.

## **ETHICAL CONSIDERATIONS**

1.24 The study was guided by the British Sociological Association's statement of Ethical Practice (2002). It was not envisaged that any ethical issues would arise, given that this was primarily desk based research and mostly concerned with material already in the public domain. However, issues of anonymity and confidentiality were taken into account in relation to the consultation exercise. The study has met the requirements of the Data Protection Act 1998.

## **LIMITATIONS OF THE STUDY**

1.25 The major limitations on the study have been the timescale and budget available, given the wide range of study objectives and amount of literature involved. While the research team has endeavoured to be as rigorous as possible, we have not been able to include unpublished work nor to search for references as thoroughly as we would wish, for example, conducting hand searches of key journals and visiting specialist libraries. As stated above, it was necessary to agree a deadline after which no further sources would be searched and, later, a deadline after which no further material was entered onto the database, for example, papers requested prior to that date which did not arrive for some time.

1.26 Given these constraints, we do not claim that the material is comprehensive, although we believe most key references for each topic have been included.

1.27 As noted above, scoping studies do not involve an explicit assessment of the quality of individual studies, nor the relative value of the evidence reviewed. Therefore, while this report gives an indication of the methodologies used, for example, the relative number of

studies employing qualitative or quantitative methods, no evaluation is offered of their scientific merit.

1.28 There is a danger that small scale consultations may appear tokenistic. A wider exercise, involving a larger number of organisations of disabled people more closely in the design and execution of the study, would have been preferable, had time and resources allowed.

## **PART TWO: FINDINGS**

### **INTRODUCTION**

2.1 This part of the report is divided into 15 sections, each presenting the main findings in relation to a key topic. Decisions about which topics merited a separate section were informed by the content of the research specification and our own research proposal, by judgments about the relative significance of different aspects of the subject, the need to avoid excessive repetition and, as indicated in Part One, a desire to avoid an impairment-dominated approach. It was decided to create separate sections for most of the key topics listed on page 11, except needs, users' views and good practice. These were pervasive issues which cropped up under every section and thus are addressed throughout the report. Three new categories were created, reflecting the volume and specificity of literature in certain areas – transitions to adulthood, goods and services, and equality and diversity. However, in line with current approaches, equality and diversity issues are also incorporated throughout the report. Studies about specific impairment groups – those with early onset dementia, people with sensory impairments and individuals with profound multiple impairment were incorporated as appropriate within existing sections.

2.2 Each section begins by setting out a brief 'publications profile', that is, the number and format of publications reviewed in relation to that topic (e.g.: briefing papers, reports, journal articles) and type of evidence (e.g.: literature reviews, research studies, national statistics). As there are only a small number of theoretical papers involved (since disability theory seldom focuses on needs or services), these were classified as 'literature reviews'. Publications which described services without presenting original research were classified as 'service reviews'. The geographic location of the research (e.g.: Scotland, the UK, international) is also given. Studies known to have been conducted in Scotland and at least one other part of Britain are classified as 'UK' while those only conducted in England, say, are classified as such. However it was striking that many authors did not specify where evidence was collected, or referred to English studies as 'national'. Where possible, efforts were made to gain more accurate information, for example, by contacting the authors, but lack of time meant this was not always feasible. It is safe to assume, therefore, that some studies classified as 'UK' were probably only conducted south of the border. The number of studies including users' views is also recorded by section.

2.3 Following the publications profile, statistical data are presented, where available, and the thematic findings relating to that topic. Where possible, good practice examples and aspects of the topic requiring further research are identified.

2.4 As explained in Part One, many studies cover more than one topic: thus, there is considerable overlap between the research discussed under different sections.

2.5 Our judgement about the order in which to present the various topics was informed by the fact that, for many disabled people aged 16-64, education, employment, income levels, transport and housing are key everyday concerns. Health and social work services are not necessarily the main priority. Indeed, some disabled people feel they should not have to become 'service users' or 'social work clients' in order to gain the necessary support to lead an ordinary life (Stalker and Reddish 1996).

## SECTION 1: EQUALITY AND DIVERSITY

### Publications profile

2.6 This section covers evidence relating to equality and diversity, including issues of discrimination and prejudice, and the interaction of disability with ethnicity, gender and sexual orientation. Overall, more research was identified than was expected, although some areas remain very little explored.

#### **This section is based on 32 publications:**

- 19 reports
- 8 journal papers
- 1 briefing paper
- 1 book
- 1 book chapter
- 1 web publication
- 1 not known

#### **Type of evidence:**

- 20 studies, 8 using qualitative methods, 6 using quantitative methods and 6 using a mix of methods
- 1 national statistics publication
- 5 literature reviews
- 4 service reviews
- 1 set of consultation responses
- 1 not known

#### ***Location of research***

- 15 in Scotland
- 11 in the UK
- 5 in England
- 1 n/a

*Disabled people's perspectives included in 23 publications*

### Summary of main findings

#### *Prejudice and discrimination*

2.7 Research by the Disability Rights Commission and Capability Scotland (2004) found a disturbing level of 'hate crime' against disabled people in Scotland. About half (47%) of the 158 respondents had experienced hate crime due to their impairment, people living in urban areas being more likely to have been frightened or attacked than those in other locations. Verbal abuse and intimidation were the most prevalent forms of harassment but physical attacks constituted a third of reported incidents. About a third of victims experienced attacks at least monthly, with the perpetrators usually strangers. Forty-five per cent of the victims had informed the police but little action was taken, due to lack of proof or interest. Such attacks had significant impact on disabled people, with a third of the victims having to avoid certain places or change their daily routines. One in four had moved house. The report



recommends a new law to protect disabled people from hate crimes and a long term public education campaign to tackle prejudice.

2.8 It is interesting to compare these findings with the results of a survey conducted by the Disability Rights Commission (2002) in Scotland, looking at public awareness of discrimination faced by disabled people. Just over half the 1000 respondents had heard of the Disability Discrimination Act 1995 (an improvement since a similar survey the previous year), with 85% of the respondents knowing that it was illegal to discriminate against people because of 'disability', although there was low awareness of new rights for disabled people forthcoming under the Act. Over half the sample believed disabled people were not treated fairly by society; almost two thirds thought they were under-represented in public positions and only a third thought disabled people were treated fairly by employers.

2.9 Negative attitudes towards people with dementia have been identified as being a serious obstacle to the development of dementia services (Scottish Executive 2004f). In addition, surveys carried out by Alzheimer Scotland (2003) have shown that a significant minority of the population still believes that dementia is a natural consequence of old age and more worrying that people with dementia are 'figures of fun'.

2.10 The Scottish Executive (2002) reports the results of a consultation with disabled people about developing an equality strategy. This identifies various barriers to participation in consultations and difficulties reaching disabled individuals at grassroots level. It is suggested that, to be effective, disability groups must accept their diversity and work together, but also that the Scottish Executive needs to acknowledge its perceived ignorance of disability issues, including diversity. Proposals are made for more effective consultation.

2.11 A different form of disadvantage is discussed by Capability Scotland (2001) in a survey investigating the financial circumstances of disabled people and their families, while Ebrahim et al (2004) and Abbots et al (2001) explore the links between socio-economic factors, impairment and ill health. There is of course a substantial literature on the association between health and socio-economic status. Social class factors are also explored in a UK study of disabled university students (Riddell, Wilson and Tinklin 2002). Social security and income maintenance benefits, health and education are all discussed in more detail later in this report.

2.12 There is a small but growing literature on the views and experiences of disabled parents in the UK: more work has been done about parents with learning disabilities than those with physical or sensory impairments. Olsen and Wates (2003) provide a review of policy and research in this area, noting that many studies are based on the assumption that disability is an individual characteristic that can be expected to impact negatively on parenting. In contrast, research informed by the social model highlights the social and economic contexts in which parenting takes place. Prejudiced attitudes towards disabled people as parents, their access to facilities and resources, and service planning and delivery have a far greater impact on parenting than impairment per se. The review concludes with a checklist of questions for local authorities and other agencies wishing to improve their policy and practice in this area.

*Disabled people from Black and minority ethnic (BME) communities: statistical information*

2.13 Black and minority ethnic groups have a younger age profile than the population as a whole. Hence the proportion of disabled people of all ages who are from minority ethnic groups is much lower than the proportion overall (Census 2001). Considering only the 16-64 age group, Pakistanis have the highest proportion of people with a limiting long-term illness: 18% compared with the majority 'white Scottish' proportion of 17%. Other minority ethnic groups identified in Census 2001 have lower than average proportions of this age group with a limiting long-term illness. In some cases the proportion is much lower, with only 8% for both Chinese and African people.

2.14 Age standardised prevalence rates for disability in the UK in 1996/7 were significantly lower for the combined Indian/Pakistani/Bangladeshi group than for the white population (Grundy et al 1999). This result contradicts the evidence of the census in relation to Pakistanis referred to above, an effect likely to be caused by differences in definition.

*Disabled people from Black and minority ethnic (BME) communities: research*

2.15 Little research has been carried out in Scotland about the needs of, and services to, disabled adults from BME communities. The small number of studies identified has tended to focus on one geographical area or one impairment group. Some of the research reviewed was not primarily about BME communities.

2.16 An audit of research on BME issues in Scotland (Netto et al 2001) found that little national, regional or longitudinal work had been carried out. Most studies were small scale, qualitative and confined to local areas. Few had evaluated the mainstreaming of race equality issues within public organisations. Much research has focused on housing (reporting that many people live in poor and unsuitable accommodation), education, social care and health issues. Less work has been carried out about access to justice, employment, poverty and rurality.

2.17 The little research which has been conducted about BME disabled people in Scotland points to a high level of unmet need. Recurring themes include a lack of awareness of services, poor information provision and cultural insensitivity within services. For example, a survey by the Disability Rights Commission (DRC/ CERES 2004), looking at the information needs of disabled people from BME communities, found their overall experience was of 'comprehensive marginalisation', with difficulty obtaining appropriate information from organisations. Agencies often failed to anticipate the real costs of providing translation services and interpreters and some displayed a negative attitude towards people with complex communication needs. It has been suggested that low literacy levels among community language speakers makes written information of little value. However, the Glasgow Anti-Racist Alliance (2003) found that language barriers were rarely a factor in low service take up, with most families going to great lengths to try to find out what services were available. It has also been suggested that disabled people in BME communities in Scotland lack established networks and have little or no contact with white disabled people. The Glasgow study found that services targeted at BME groups have proved successful, with demand outstripping supply.

*Disabled people from Black and minority ethnic (BME) communities: specific services and impairment/ ethnic groups*

2.18 The need for specially designed or adapted housing provision within BME communities remains largely unmet (Netto et al 2003). The Glasgow Anti-Racist Alliance (2003) reported that most young BME disabled people were accessing some mainstream agency, often social work, yet carers often lacked effective support: there was a desperate need for more short breaks services.

2.19 Disabled people from BME communities are poorly represented in the labour market (Labour Market Trends 2002). A study of supported employment schemes across the UK found few BME individuals were involved (Weston 2001). An evaluation of Women into Work Schemes (Howieson 1996), which included unemployed disabled women from BME communities in Edinburgh, found that the project had helped raise confidence and self esteem and provided useful information, job-seeking skills and work placements. In relation to the benefits system, the Disability Alliance (2004) identified many serious deficiencies which impact adversely on BME claimants, whether disabled themselves or caring for a disabled person. Support arrangements were patchy, variable in quality and poorly publicised. A range of recommendations are made for improving the system.

2.20 In relation to particular minority ethnic groups, an English study looking at outcomes of community care services for Asians found that, despite having significant needs, confidence and trust in services was low. Many people experienced isolation, forced dependency on family members and frustration at not being able to move about their home freely. They lacked information about their entitlements and how to access services. Respondents felt service providers often lacked cultural knowledge, expecting Asians to fit into existing provision. Again, suggestions for improving services are made, including consulting the Asian community about needs and priorities, promoting peer support and social contact, providing housing and aids and adaptations that take account of people's preferences and religious and family duties, as well as transparent, non-discriminatory decision making.

2.21 Many of these points are echoed in a UK study about disabled refugees and asylum seekers (Roberts and Harris 2002). There are no reliable statistics about the prevalence of impairment and chronic illness among this population but this study alone identified well over 5000 individuals. Areas of high unmet need included personal care, suitable housing, aids and equipment and knowledge about entitlements. Again, communication difficulties and extreme isolation were identified. In relation to service provision, the authors found an urgent need for better joint working between relevant agencies. Over-stretched resources meant that the needs of disabled refugees and asylum seekers were sometimes given less priority than those of 'local' disabled people.

2.22 Some research has focused on the needs of BME people with particular impairments. Darr et al (1996) conducted a UK wide study of projects and initiatives for Deaf people from BME communities. They identified a number of cultural and social groups led by Deaf BME people, showing the importance of religious and cultural identity, but also found that some found it hard to learn about their own ethnicity and religion. Some BME Deaf people experienced racism from white Deaf people and were marginalised within their own communities. Most service initiatives focused on Asian and Afro-Caribbean Deaf people and/or their families, and were located in large cities. Provision for other BME groups was

poor, with little on offer to older Deaf people and those who are deaf-blind. Voluntary sector initiatives faced ongoing funding difficulties and their mainly Deaf staff were generally poorly supported and trained. BME workers in the statutory sector, who were mostly hearing, often faced racial hostility from white colleagues. Developing services which take account of cultural needs has also been recommended as a way to improve services for people with early onset dementia (Quinn 1996).

2.23 In summary, the DRC/CERES (2004) concludes that the majority of services are not yet ready to take on board the complex needs of disabled people from BME communities. Some agencies view BME service users as non-conformist, because they do not 'fit' available services. The stereotypes persist that people 'look after their own' and/or choose not to access services. There is little monitoring of service take-up by BME disabled people in Scotland. Much closer joint working and information sharing between statutory and voluntary sectors is needed to develop good practice in relation to race and disability equality. Specific gaps in current provision in Scotland include projects supporting young people, including siblings, carers groups, peer support groups, short breaks services and accessible information and advice services.

#### *Disability and gender*

2.24 There is very little research about disability and gender in Scotland. At a theoretical level, a number of disabled academics have discussed the need to incorporate feminist perspectives into the social model (eg: Morris 1992, Thomas 1999): however, this discussion is outwith the remit of the present study. Sheldon (1999) argues for a 'less individualistic' approach, to enable recognition of commonalities among disabled people and thus, the forging of coalitions. Begum (1996), discussing the power exerted by the medical world over the environment in which disabled people live, draws attention to the way GPs respond to the needs of disabled women. The accounts of disabled women facing violence and sexual abuse from their partners are reported by Hendey and Pascall (1998), who conclude that these experiences undermine independent living policies, while Sale (2001) argues that all women's refuges should be made physically accessible and staff trained in disability awareness. Differences in 'social power' between disabled and non-disabled people and between men and women result in a 'double whammy' for some disabled women; for example, when an abusing partner is also the main 'carer'. On a more positive note, the benefits of training schemes designed to help disabled women find paid employment were noted above.

2.25 There has been little research about gender and disability in relation to men. Robertson (2004) notes that, although the disability movement may have been dominated by men, there has been some avoidance of exploring 'men's issues'. Similarly, despite increasing sociological interest in masculinity, few studies have examined men's subjective experience, far less sought the accounts of disabled men. Robertson cites a review by Shakespeare (1999) which only identified one such study, before going on to discuss work in relation to the sociology of the body.

2.26 Only two studies looking at disabled men have been identified in this research – Ebrahim et al (2004) exploring the association between class and disability of 5773 men across the UK, and Wilde (2004) on soap operas as an 'alienating experience' for disabled

men. Again, the latter can be seen as part of a wider literature about cultural representations of disability (eg: Shakespeare 1997, Darke 2004) which is beyond the scope of this study.

### *Sexual orientation*

2.27 Little research has been conducted about the needs and experiences of the Lesbian Gay Bisexual and Transgender (LGBT) community in Scotland (Morgan and Bell 2003 quoted in Communities Scotland (2004)), still less about its disabled members. It seems that more attention has been paid to LGBT people with learning disabilities than those with physical or sensory impairment. For example, Partners in Advocacy is currently carrying out research about people with learning disabilities in Scotland who have, or may wish to have, same-sex relationships while Abbott and Howarth (2005) have conducted a UK wide study on the same topic. However, The Equality Network ([www.equality-network.org](http://www.equality-network.org)) and the Disability Rights Commission have received funding from Communities Scotland to carry out research into how well LGBT organisations and disability organisations support disabled people: the nature of the research is yet to be determined. Communities Scotland is also funding research looking at the housing and housing related needs of older (aged 45 plus) LGBT people, to be published in May 2005. The study team has written a draft literature review.

2.28 At the University of Surrey, Freda (work in progress) is conducting a study examining discrimination in employment focusing on 'cross-issues' including the experiences of disabled lesbians and gay men. The Disability Rights Commission is currently engaged in a project researching key features of multiple identities in the UK and Ireland, including access to health services by disabled gay men, lesbians and bisexuals.

### *Multiple identities*

2.29 A few studies refer to the experiences of people with 'multiple identities' who may face multiple discrimination. A study by Molloy et al (2003), unusual because this was its main focus, explored diversity among disabled people, taking account of ethnicity, age, gender and sexuality. Diversity was generally viewed positively by the disabled respondents, with opportunities for disabled people from all groups believed to be improving. However, Black Caribbean and African, and white gay and lesbian, disabled people were more likely than others to have experienced discrimination. How far individuals were able to overcome disadvantage was attributed to their ability to access personal, emotional, practical or financial resources.

2.30 The Disability Alliance (2004) notes that most organisations do not address poverty issues, although BME disabled people are disproportionately affected by these. Asian women who do not speak English face multiple disadvantage within the benefits system, on the grounds of ethnicity, language and literacy skills, social isolation, cultural attributes and gender.

## **Good practice**

2.31 As there are so few evaluations of good practice in this area, it is difficult to identify relevant evidence. However, in relation to services for disabled people from BME communities, the DRC/ CERES report (2004) pinpoints the following elements of good practice:

- the standard provision of translating and interpreting
- supported referrals
- accessible information provision and advocacy
- training bilingual staff in signing and social care
- targeted publicity and outreach work
- technological upgrading
- customising information to improve its visibility to BME disabled people
- consulting people about their needs and perspectives
- following consultation, ensuring feedback is given about action to be taken.

## **Gaps in the evidence base**

2.32 Areas identified as requiring further research include:

- diversity, identity and active citizenship
- different models of police response to complaints from disabled people about harassment and attacks
- views of disabled people from Black and minority ethnic groups in Scotland about how best services can meet their needs
- overview of health and social care provision in Scotland for disabled people from BME communities, including people with profound multiple impairment
- action research relating to development of ethnic monitoring systems
- evaluation of race equality policy and practice in key policy areas
- disabled men's support needs and experiences of services
- the views and experiences of disabled LGBT people.

## SECTION 2: NEEDS ASSESSMENT

### Publications profile

2.33 Publications included in this section do not all have needs assessment as their main focus: some are primarily about service delivery but include some data on assessment. However, Davis et al (1998) explored access to assessment for disabled people while more recent studies have tended to concentrate on assessment for particular impairment groups or assessment for specific services. Some common themes clearly emerge from the findings.

**This section is based on 28 studies:**

- 13 reports
- 11 journal papers
- 2 briefing papers
- 1 conference abstract
- 1 book chapter

***Type of evidence***

- 18 research studies, 7 using qualitative methods, 1 using quantitative methods and 10 using a mix of methods.
- 6 literature reviews
- 4 service reviews

***Geographic location***

- 16 in Scotland
- 8 in the UK
- 3 in England and Wales
- 1 International

*Disabled people's views given in 16 studies*

2.34 According to the Audit Commission's latest published figures there were 47,831 (15.2 per 1,000 population) community care assessments or reviews for people aged 18-64 with physical impairment in 2003-2004 (see <http://www.audit.scotland.gov.uk>). This represents an increase over the previous two years figures.

### Summary of main findings

*Disabled people's views and experiences of assessment*

2.35 Davis et al (1998) explored the perspectives of practitioners, disabled people and carers, drawn from six social services teams in England, about access to assessment. The respondents found the process of assessment, and particularly their encounters with social services departments, confusing and fragmentary and, in many cases, irrelevant to their own priorities. Users' views often differed from professional perceptions (a point echoed by Boa and McFadyen 2003, Begum 1996 and Heywood 2004). For example, practitioners often failed to take account of the complexity and mutuality of many caring relationships, tending to pigeonhole individuals as either 'users' or 'carers'. Most social workers' decisions about access to assessment were influenced by service criteria focusing on risk and by budgetary considerations: disabled people and their carers generally saw risk in a broader perspective

which practitioners were slow to recognise and respond to. In some cases, practitioners not only failed to seek the disabled person's views, they conducted the assessment through a series of telephone calls to other practitioners and relatives without ever meeting the individual concerned. Some disabled people did not know they had been assessed.

### *Needs assessment for different groups*

2.36 Various studies have identified difficulties in assessing the needs of particular groups. For example, very little is known about the housing and community care needs of people living in rural areas, where needs may be more hidden than in urban communities (Field and Oldman 1997). Recent advances in approaches to assessing need do not translate well into sparsely populated areas. In a study of assessment and care management across Scotland, Stalker and Campbell (2002) found that little thought had been given to how best to involve people from Black and ethnic minority communities in the assessment process. Several studies have reported the difficulties in assessment and planning experienced by young disabled people approaching adulthood: these are discussed in the following section.

2.37 A study of social work services for people with sensory impairment in Scotland (Scottish Office 1998) reported that assessment arrangements were often ad hoc, and involved considerable delays. More work is needed to identify the numbers and needs of deaf-blind people across Scotland: the Section 7 Guidance in England may be useful here. Some Scottish authorities are working to ensure people with sensory impairments are included in single shared assessments. These findings should be read in the context of an Action Plan for services to people with sensory impairments having been published recently (Scottish Executive 2004a).

2.38 The 2002 study of care management found that about half of Scottish local authorities did not routinely offer carers an assessment of their own needs. It is not known if this has changed since the implementation of the Community Care and Health (Scotland) Act 2002 which gives carers an automatic right to assessment of their ability to provide care, and need for services, irrespective of whether the person they support is being assessed or using services.

### *Geographical and organisational variability*

2.39 Davis et al (1998) found that, although English local authorities issued guidelines about assessment, local social work teams determined eligibility differently. In addition, there were variations by type of team, with specialist teams being more likely to offer disabled people a comprehensive assessment and other teams providing low level assessments. Similarly, there are variations in assessment arrangements across Scotland, with some areas having specialist teams to meet the needs of people with all types of sensory impairment, and other areas having teams for each impairment. In some places the local authority is the direct service provider, in others, service provision is contracted out to voluntary organisations. It is suggested that these variations may lead to unevenness in the conduct of assessments. Variation has also been found in the implementation of direct payments across Scotland (Witcher et al 2002). While most authorities applied the eligibility criteria set out in the regulations, there was considerable uncertainty in some areas about how to interpret the requirement that a person must be 'willing and able' to manage a direct payment, with



outcomes heavily dependent on the attitudes of individual care managers. However, this research was conducted prior to the implementation of the Community Care and Health (Scotland) Act 2002 which made it a duty, rather than a power, of local authorities to offer direct payments, and before revised guidance was issued.

#### *Benefits of a holistic, multi-disciplinary approach to needs assessment*

2.40 A number of studies highlight the benefits of a holistic approach to assessing housing and community care needs (eg: Field and Oldman 1998, Heywood 2004, SCIE 2004, Stalker 2002). For example, Heywood reports that while most of the 104 disabled people in a study (conducted in England and Wales) were pleased with the adaptations made to their houses, some had been carried out in a disempowering way, failing to take account of 'precious aspects' of the home or family relationships. The importance of close collaboration between professionals and multi-disciplinary approaches to assessment are recurring themes (Stalker and Campbell 2002, Cordney et al 2002, Grewal et al, 2004, Field and Oldman 1997).

#### *Delays and omissions*

2.41 Delays in carrying out assessments are reported across the UK: Grewal et al (2004) discuss the underlying reasons and some practical approaches to overcoming the problem. Some studies identify gaps in assessing needs, including failure to pick up mental health problems in people with profound multiple impairments. Enough effort is not always made to ascertain the views of individuals with sensory and /or communication impairments during the assessment process.

2.42 A recurring theme reported by authors reviewing the needs of people with early onset dementia is whether there should be separate specialist services for younger people with dementia or generic services which are often services for older people with dementia (Tindall and Manthorpe 1997, Beattie et al 2002, SNAP 2000, Quinn 1996). Difficulties in assessing people with early onset dementia relate, in part, to difficulties in inclusion criteria. For example, alcohol related disease may be included in some studies while Huntington's and head injury are excluded (Woodburn and Johnstone 1999a).

2.43 In addition, assessment instruments are not always sensitive to early onset dementia as they have been designed for people over 65 with dementia (Woodburn and Johnstone 1999b). Taking into account these limitations in assessment measures, one study found that the level of impairment is milder for those with alcohol related disease (Woodburn and Johnstone 1999b). Where assessments should take place and the objectives of assessment have been considered for those with early onset dementia, CHSR (1999) has suggested that this should be carried out in the community with the aim of keeping the person at home as long as possible.

## *Costs*

2.44 Very little research was found about the costs associated with needs assessment. However a study by Brand et al (1995), exploring the impact of contract setting on residential care for disabled people, analysed individual costs and aspects of assessment. The authors argue that using the Barthel Index as part of the screening process can help match needs and resources effectively.

## **Good practice**

2.45 Aberdeenshire has been identified as a model of good practice in assessment and care management (Stalker and Campbell 2002). It has the following features:

- Written criteria for eligibility for care management, targeted at people assessed as having complex needs
- Delegated budgets to care management level, giving staff a high level of autonomy in purchasing decisions
- Innovative and complex care packages to meet assessed needs, sustaining people with complex needs in their own homes
- Evidence that the assessment process was clearly explained to service users and their families
- Carers' own needs assessed separately.

## **Gaps in the evidence base**

2.46 A fair amount of research has been carried out on needs assessment in Scotland so overall this is unlikely to be a top priority. However the following areas have, or can be, identified as requiring further investigation:

- disabled people's experiences of assessment following the introduction of single shared assessment procedures
- meeting the needs of people with sensory impairment, with a focus on identifying necessary changes within current community care services so that existing inconsistencies and specialist needs are addressed
- the impact of costs of providing services for people with sensory impairment in rural areas and the differences or cost/benefits of direct service provision as opposed to contracting out to the voluntary sector
- numbers and needs of deaf-blind people in Scotland
- different models for involving people with severe and complex impairments in setting rehabilitation goals.

## SECTION 3: TRANSITIONS TO ADULTHOOD

### Publications profile

2.47 Relatively little research about transitions of young disabled people to adulthood has been conducted which is specific to Scotland. However more studies have been conducted south of the border. Two reviews have been published – one covering Scottish research (Stalker 2002) and one covering UK and some international literature (SCIE 2004). There are no national statistics relating to this topic.

#### **This section is based on 14 publications:**

- 2 briefing papers
- 8 reports
- 3 journal papers
- 1 book chapter

#### ***Type of evidence:***

- 3 literature reviews/ theoretical papers
- 1 service review
- 10 studies, 6 using qualitative methods, 2 using quantitative methods and 2 using a mix of qualitative and quantitative methods

#### ***Location of research***

- 7 in Scotland
- 1 England
- 4 in the UK
- 2 international

*Young disabled people's perspectives included in 10 publications*

### Summary of main findings

#### *Young people's views*

2.48 A recurring theme in the research is that often young people are not adequately consulted about their views in general, and about transition planning in particular. In addition, young people's views may differ from those of professionals. For young disabled people, leaving school is a multi-faceted experience in which making and maintaining friendships, finding work opportunities and studying are likely to be given equal importance (Stalker 2002). There is some evidence however that professionals and service providers tend to see transition more narrowly, in terms of the need to move young people from children's services into adult provision. Similarly, while young people value inclusive leisure for its opportunities for friendships and fun, professionals tend to view it as a way for young people to learn life skills and develop greater independence and /or self esteem. Young disabled people can feel apprehensive as they approach and negotiate the transition to adulthood: for some, this can be a time of sadness and loss of friendships, for example where difficulties are experienced keeping up with friends on leaving school. Watson et al (2000) explored young people's perceptions about identity and difference while Pearson (undated) concluded that

young disabled people did not see impairment as negative but believed that other people did. Her informants found that their self-confidence and self-esteem increased as they grew older, and through involvement in organisations which supported them in an empowering way.

### *Planning for transition*

2.49 During the 1990s, a number of studies reported on the strengths and - more often - weaknesses of the current approach to transition planning in Scotland, centred on Future Needs Assessment. Several studies highlight the difficulties experienced by young people and their families in trying to obtain information about post-school options, especially in accessible formats. Translated materials are not always available and the provision of interpreters is variable across Scotland. Young people with complex needs and communication impairments are particularly likely to be left out of planning. Some local authorities now have a policy that no school leavers go to day centres. Nevertheless, lack of good information inevitably leads to lack of real choice, and many young people in Scotland are still directed towards day centres and segregated FE college courses. Sometimes those advising young people lack information on other options, particularly about work opportunities and inclusive further education. It has been suggested that training programmes for young disabled people have not always been person-centred or particularly useful and that supported employment has more to offer the young person, especially in terms of gaining financial independence.

2.50 From Autumn 2005, the Future Needs Assessment process will be replaced by a new transitional planning process to be introduced under the Education (Additional Support for Learning) (Scotland) Act 2004. Individual Records of Need will be replaced by Co-ordinated Support Plans and education authorities will have new duties in relation to planning for a young person's future. In addition, parents and pupils will have new rights to information and involvement. Nevertheless, evidence from research on Future Needs Assessments highlights important lessons for any transition planning process. It must be centred on the young person's views and it must plan for seamless services which will support the young person towards independence (SCIE 2004). Ineffective planning is likely to result in young people dropping out of services. The goals of planning should be to provide high quality services, to offer young people choice and control and to maximise their educational, training, employment and social opportunities.

### *Leisure/ social relationships*

2.51 Although leisure opportunities and friendships are important to young disabled people, many have little experience of an independent social life. Hughes (2005) notes that restricted opportunities for leisure and consumption constitute a major social disadvantage, suggesting that for some young people, 'leisure' is little more than a series of activities designed to keep them occupied and supervised. Other research has shown that young disabled people are interested in becoming involved in a wide range of indoor and outdoor activities, none of which are impractical or excessively expensive. However, lack of appropriate support (transport, personal assistance and support for communication) is a major barrier to many young people participating in ordinary leisure activities, particularly those with complex impairments and/or high support needs. Deaf youngsters face particular barriers accessing leisure opportunities, including the attitudes of some staff both in leisure

centres and on public transport, and difficulties communicating with other young people. Young disabled people's ability to communicate with each other and develop friendships can also be restricted by excessive adult surveillance (Watson et al 2000). A few studies have suggested that young people's experiences at school have a significant and often negative impact on their ability to develop friendships and social activities outside school, with many feeling isolated, lonely and left out. This may be due to barriers to forming friendships within mainstream schools or the difficulty, for those at segregated schools, of seeing their school friends outside school hours and forming friendships with children at other schools.

### *Policy and service developments*

2.52 SCIE (2004) notes that it is 'a government priority' to ease the transition process for young disabled people by providing a range of effective services within health, social care, education and employment but that the relevant legislation and policy guidelines are still evolving. The overall aim is for young disabled people to have access to effective transitions services on a par with those available to any other youngsters. It is important to bear in mind that each young person has different support needs and their own timescale for negotiating transition to adulthood. However, research repeatedly points to the failure of different agencies to plan and work together. For example, the transition from children's health services to adult provision may be far from smooth and can lead to poorer service provision and/or deterioration in health. Grewal et al (2004) explore how and why structural transitions in disabled people's lives, including the transition to adulthood, may result in discontinuity of services. In addition, Hughes (2005) suggests young people remain frustrated by the gap between government policy and rhetoric and their experience of facing physical barriers on a daily basis.

2.53 Some positive initiatives have been undertaken in Scotland over recent years. These include implementation of the Beattie Report and the Special Educational Needs and Disability Act 2001. Direct payments were extended to 16 and 17 year olds through the Regulation of Care (Scotland) Act 2002. As noted above, the Education (Additional Support for Learning) (Scotland) Act 2004 will come into force from Autumn of 2005. South of the border, Grewal et al (2004) note a range of policy developments to facilitate the transition process and overcome some of the barriers identified above, including the Connexions Service and Access to Work schemes, but suggest it is too early to judge their effectiveness.

### *Housing*

2.54 Very little research has focused on housing and young disabled people in Scotland but a study by Dean (2003) found that many had similar aspirations to their non-disabled peers. Most wanted to move out of their parents' home at some point and expected that, in time, they would form a new household with a partner and /or children in appropriate housing. Disabled young people took similar routes to leaving home as others. However, a few did not wish to leave the parental home, sometimes as a positive choice, sometimes apparently because of lack of information about alternative housing and support options. Most parents thought their sons and daughters would eventually leave home although a few were opposed to such a move.

### *Wider social context*

2.55 A number of studies point to the wider social context, and particularly the physical, social and attitudinal barriers facing young disabled people, which can make the search for identity and the transition to adulthood more difficult. Barriers in the form of use of physical space and segregated schooling are reported while difficulties securing and maintaining employment are also discussed. The negative effects of other people's attitudes are explored, with young disabled people feeling strongly that attitudes must change. Bignall and Butt (2004), in an English study exploring barriers to young black people achieving independence, highlight the significance of cultural, ethnic and religious factors in influencing the extent to which young people felt they had become 'independent'. Many reported experiences of being treated 'differently', with Deaf Asian youngsters feeling particularly isolated.

### **Good practice**

2.56 The SCIE review (2004) describes 'good practice' in transition planning as follows:

- specific service provision which is multi-disciplinary, holistic, planned/ anticipatory, and ensures some continuity
- staff working with young people receive training in transition planning
- the young people themselves are closely involved in the planning process, and offered appropriate support for that involvement
- young people are given information and choice and reassured about confidentiality
- focus is on an individual's strengths rather than perceived deficits
- cares and families are also involved, supported and treated with sensitivity
- particular attention is paid to young people with communication impairments.

2.57 Cameron and Murphy (2004) argue that the low-tech communication system Talking Mats could be used to facilitate transition planning, Life Plans and to explore sensitive issues with young disabled people, particularly those with communication difficulties.

### **Gaps in the evidence base**

2.58 Watson et al (2000) suggest a need to carry out in depth research on the transition of young disabled people to independent adulthood. Elsewhere, more specific topics identified as requiring further investigation include

- outcomes of, and satisfaction with, the transition process among young disabled people
- young people's views about the type of services which should be available and ways in which they can be consulted and involved in aspects of service planning and delivery
- the role and tasks of transition workers
- teenage clinics
- more work on children with physical impairment as opposed to those with chronic conditions, which tends to dominate research on transitions

- the effectiveness of different post-school transition models.

2.59 Watson et al (2000) also make the important point that future research on childhood and youth should always take account of disability and include some disabled children. There is scope for useful comparisons between the experiences of disabled and non-disabled young people.

## SECTION 4: EDUCATION

### Publications profile

2.60 There is a relatively high proportion of Scotland specific research about education.

#### **This section is based on 22 publications:**

- 1 report of conference proceedings
- 1 abstract of conference paper
- 11 reports
- 7 journal papers
- 1 ongoing
- 1 survey review

#### ***Type of evidence:***

- 4 policy and literature reviews
- 14 research studies, 3 quantitative, 6 using qualitative methods, 1 using qualitative methods, 3 using a mix of qualitative and quantitative methods, 1 exploratory
- 2 theoretical paper
- 2 national statistics

#### ***Location of research***

- 15 in Scotland
- 5 in the UK
- 1 Scotland and England
- 1 international

*Disabled people's perspectives included in 14 publications*

### Summary of main findings

#### *Statistics*

2.61 SHS statistics on educational attainment and qualifications of disabled people do not distinguish people by type of impairment. Statistics on the numbers of disabled students are collected by the Higher Education Statistics Agency and the Scottish Further Education Funding Council and results for 2001/2 are published in Social Focus on Disability (Scottish Executive 2004b). In 2001/2 4% of all students had declared a disability. Some differences are noted in the proportions of disabled students taking various subjects compared with non disabled students (Table 4.11). For example, disabled students were less likely to study business administration and more likely to study creative arts or social studies than non-disabled students. Disabled students were slightly more likely than non disabled students to achieve a first or second class degree. More recent data (Higher Education Statistics Agency 2004) show a small increase in numbers of disabled students. In 2002/03, 5% of those in Scottish HE institutions declared a disability. Dyslexia was the most common form of impairment, followed by invisible conditions such as diabetes, epilepsy and asthma.

#### *Barriers to education*



2.62 In a study published nearly ten years ago, Baron et al (1996) note that, even in training and educational courses underpinned by notions of ‘empowerment’, like social work, disabled students faced a number of obstacles when compared to non disabled students. The study found, for example, that disabling environments in terms of the inaccessibility of institutional buildings could effectively reduce the ‘choice’ of places to study to one institution, and even then students reported major difficulties in accessing teaching rooms, libraries and accommodation. The researchers also found that assumptions were often made about the consequences of students’ impairments rather than considering the disabled students’ individual and actual needs. Later research by Edinburgh and East of Scotland Deaf Society (2001) found that mainstream schools were unwilling to pass on information about the research study they were conducting to young Deaf people because it was thought not to be of interest to them. Thus these young people were not being given information that was potentially relevant to them. The study further found that Deaf young people in mainstream schools lacked information and knowledge about specialist equipment and the benefits it could bring them in terms of access to social, cultural and leisure opportunities.

2.63 The amount and suitability of information regarding post-school options for disabled young people making the transition into adulthood was an issue identified by Stalker’s (2002) research, as discussed in the previous section on transitions to adulthood. In a study investigating the education and employment experiences of young disabled adults in Scotland, Baker and Hersh (2003) found that most participants found their educational experience positive with the exception of career guidance, which had seemed unambitious or even ill-informed. Thus low expectations from service providers and insufficient provision may be holding some young people back from appropriate opportunities.

### *Equal opportunities*

2.64 In 1998(a), Riddell argued that barriers remained to full participation in higher education and that some were being re-enforced by attempts to widen access and thus increase equality of opportunity for disabled people. Moreover, while the barriers encountered were structural, policy makers essentially saw them in individualised and medical terms. In some cases students were being provided with assistance to get round obstacles that should have been removed (Tinklin and Hall 1999). Such structural factors were often compounded by the self-defence strategies used by disabled students. For example, students could be reticent to disclose impairment on application forms and, once accepted for a course, they could remain reticent to contact the institution to inform them of their needs due to fears of being labelled a ‘nuisance’.

2.65 In a study touching on issues of class, ‘race’ and gender, Riddell, Wilson and Tinklin (2002) note that a higher proportion of disabled students in higher education are male and middle class than is the case in the wider student body, and that disabled students are more likely to be white than other students. The study also identified interesting differences in understandings of disability and the ethos and nature of support, in pre and post 1992 universities. The pre 1992 universities gave students considerable direct support of a type which was described in terms of ‘benign paternalism’ by the wider access coordinator, whilst the post 1992 university had a more politicised view of disability but inadequate resources to make the full range of systematic changes it felt were needed. Thus the authors argue that we cannot understand the participation rates and experiences of disabled students in isolation

from their social class background and the patterns of social stratification within the universities they attend (Riddell, Wilson and Tinklin 2002).

2.66 The most recent research by Tinklin et al (2004) suggests that there are definite signs of progress in the development of provision for disabled students, although some areas need further attention, particularly learning and teaching. The authors note that effective change in this area means improvements for all students. MacKay (2002) argues however, that the notion of disability is being unhelpfully removed from the educational arena. In striving for inclusion, the author notes that no one's interests are served if the implications of impairment are simply ignored or wished away.

### *Improving inclusion*

2.67 Baron et al's (1996) findings suggested that organisations should ensure that a comprehensive disability policy is embedded in equal opportunity policies applying both to staff and students, and that all staff should receive disability awareness training. Also, better lines of communication were needed so that potential students felt able to disclose their impairment to institutions. Hall and Tinklin (1998) reported that whilst institutions had found ways of adapting the physical environment to improve access for disabled students, this was sometimes less than ideal. Both these studies were of course carried out before the introduction of the Special Educational Needs and Disability Act (SENDA) 2001 which outlaws discrimination against disabled students and prospective students, in higher and further education, giving institutions a duty to develop proactive disability policies.

2.68 Attitudinal change is needed as well as more resources. Edinburgh and East of Scotland Deaf Society (2001) recommends wide Deaf awareness training in schools and youth clubs by enabled Deaf young people. More accessible, visually interesting information is needed about the beneficial equipment, specialist services and facilities available to Deaf youngsters, and how to use them.

2.69 Rather than being seen as a distinct policy area, disability issues have to be embedded in all institutional policies and procedures (Tinklin et al 2004). There is a need for more effective transition services covering education (SCARE 2004).

2.70 In January 2005, the Scottish Executive published 'Partnership Matters', a guidance document for all agencies involved in making and managing support arrangements for students with additional needs in Further Education. The document is intended to clarify boundaries of responsibility between FE colleges, local authorities and NHS Boards, and to encourage partnership working to ensure the most appropriate support arrangements are put in place.

### **Good Practice**

2.71 The Scottish Executive (2005, 3.1.2) identifies a number of good practice principles for partnership working in FE, including:

- the learner must be fully involved in discussions about an appropriate education placement and the decision making process

- the needs and aspirations of the individual must be at the centre of any decision taken regarding an appropriate education placement
- statutory agencies - FE colleges, local authorities and NHS boards - must work together to ensure the most effective and appropriate learning opportunities are offered to students
- providers of post-16 education should demonstrate a commitment to inclusiveness recognising the diversity of student placements
- where colleges identify a need for support by other agencies, for example, social work and health, they will liaise with the appropriate agency to discuss how best support can be provided and will liaise with the student and the appropriate agency to discuss how best support can be provided
- the learner's needs will only be discussed between agencies with the learner's explicit consent.

### **Gaps in the evidence base**

2.72 The following gaps have been identified:

- to ensure that policy and decision-makers in education authorities incorporate disability as an equality issue, for example, by monitoring education authorities (Samuel 2001). A summary report on the readiness of Scotland's higher education sector has just been made available (Corlett 2005)
- the views and experiences of disabled people about adult education, community education and lifelong learning
- the impact of the Special Educational Needs and Disability Act 2001 (SENDA) in tackling disability discrimination in education, including new duties (from September 2005) on providers of Further and Higher Education to make reasonable adjustments to the physical environment to accommodate disabled students.

## SECTION 5: EMPLOYMENT

### Publications profile

2.73 Employment legislation in Scotland is a reserved issue for the Westminster parliament. There is however a number of Scotland specific publications in this area which can perhaps be related to the phenomena of supported employment. Although appearing too late to be included in this scoping study, a review of the evidence base relating to disability and employment in Scotland, commissioned by The Scottish Executive, has just been published (Riddell et al 2005).

#### **This section is based on 39 publications:**

- 1 report of conference proceedings
- 1 abstract of conference paper
- 27 reports
- 1 book chapter
- 6 journal papers
- 1 briefing paper
- 1 ongoing
- 1 not known

#### ***Type of evidence:***

- 7 policy and literature reviews
- 26 research studies, 9 using quantitative methods 14 using qualitative methods, 3 using a mix of qualitative and quantitative methods
- 3 national statistical data sets
- 2 international data sets
- 1 not stated

#### ***Location of research***

- 8 in Scotland
- 26 in the UK
- 1 England
- 4 international

#### ***Disabled people's perspectives included in 20 publications***

### Summary of main findings

#### *Statistics*

2.74 Significant differences between disabled and non-disabled people's experience in the labour market are highlighted in results from the British Labour Force Survey (LFS) reported in Social Focus on Disability (Scottish Executive 2004b)<sup>1</sup>. In 2003 there were 662,000 people (21% of the working age population) estimated to be of working age and with an impairment. Half of these people, compared with 86% of the non-disabled working age

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<sup>1</sup> As noted in the conclusion, the LFS does not distinguish between disability and long-term illness

population, were either in employment or unemployed but available for work (i.e. economically active). The rate of economic activity for disabled people has increased from 43% in 1999 to 49% in 2003. Three quarters of disabled people of working age who are economically inactive said they were inactive due to illness or disability. This represents approximately 257,000 people. Further information is available from the LFS on age groups, part-time working and type of impairment.

2.75 Among disabled people who do work, their earnings were 70-80% of the earnings of non-disabled workers at the time of the 1996/7 Disability Survey.

### *Disabled people in the labour market*

2.76 Employment is crucial for determining personal income resources. However the employment rate for working age disabled people is significantly lower than for non-disabled people in the UK and indeed many other OECD countries (OECD 2003a,b). Burchardt (2003) found that, of those acquiring impairment during one year, 84% of people with the least complex impairments retained their employment, while just over half of those with multiple impairments did so. Parr et al (1997) noted that it was unusual for aphasic people to return to work, although many in their study wished to do so. The authors did however find some examples of aphasic people entering employment successfully given the appropriate structures of support. Similarly, Croucher et al (2002) note that disabled graduates were more likely to be unemployed than non-disabled graduates (8.6% compared with 6.7%). Archie et al (1998) found that unemployed graduates with a visual impairment were less likely than their employed counterparts to have extensive networks to help find a job, to use their contacts in less directive ways and to socialise in more structured, group centred ways.

2.77 Even when in employment, disabled people can still find themselves financially excluded. Smith, Middleton, Ashton-Brooks, Cox and Dobson with Reith (2004) note, for example, that the unmet weekly costs for disabled people who work 20 hours per week at the minimum wage are up to £189 (for those with high – medium support needs). Moreover, fewer employment opportunities for disabled people and lower incomes in work can be related to educational outcomes, as discussed in the previous section, (Prime Minister's Strategy Unit 2005). Young et al (2000) found in their study of Deaf and hearing people working together in a statutory organisation that 90% of Deaf staff were employed in unqualified grade posts, in comparison with only 15% of hearing staff. Research has also found that disabled people in Great Britain with (higher) educational qualifications were more likely to be working than those without educational qualifications, especially women (Grundy et al 1998). Roulstone et al (2003) illustrate the 'diverse and often complex range of strategies employed by disabled people to 'strive and survive' in the workplace. The researchers conclude that much still needs to be done to understand and respond systematically to disabled workers' needs: they want access to more structured, formalised and appropriate support.

2.78 Research has highlighted that people with complex needs perceive supported employment as beneficial. Participants in Weston's (2002a) research were found to value the feelings of inclusion and sense of status that working brought, along with the increased opportunities for meeting people, making friends and a degree of financial independence. The authors argue that participants had a strong motivation to work and a pride in their work and that, by comparison, participants often felt bored in day centres. However, the report

highlights that, overall, people with complex needs are underserved by supported employment and that lack of funds in the agencies concerned essentially curtails the supported employment opportunities that can be offered to people with complex needs. In a review of the literature, Weston (2002b) echoes the benefits of supported employment and argues that, for people with complex needs, it is actually more likely than government schemes to lead to ‘real jobs for real pay’. The report points to factors that might inhibit take-up of supported employment by people with complex needs, especially women and Black and ethnic minority groups who are especially underrepresented, and argues that there is a lack of awareness amongst both employers and the wider public about what supported employment actually is. Howieson (1996) showed that disabled unemployed women from minority ethnic groups in Edinburgh had benefited in a number of ways (self-confidence and practical job-seeking skills) from the Women Onto Work Project.

2.79 Funding for supported employment is essentially ‘fragile and fragmented’ and access to it remains difficult for a large number of disabled people who might benefit. Thus there is a need for a national infrastructure for supported employment in the UK, and O’Bryan et al (2000) set out some ideas for practice.

2.80 Whilst people with severe impairment and high personal assistance needs have job opportunities and want to take advantage of these, responsibilities for personal assistance arrangements on top of full time employment can make significant demands on disabled people. They find this acceptable in many instances, provided that financial disincentives and other barriers to work, such as inadequate access and transport, employers’ attitudes and inflexible working practices are not too great.

2.81 Cole et al (2000) found that whilst many disabled people wanted to get a part-time job, existing employment services were not meeting their needs. Access to a supported employment scheme was important to secure the intensive and long-term support that people required and the study found that introducing a ‘person-centred’ planning process led to people doing more things they really wanted to do.

### *The New Deal for Disabled People*

2.82 Roulstone (2000) argues that, as a purely supply-side measure, the New Deal for Disabled People is unlikely to address the nature of employment barriers. At worst, it seriously risks misrepresenting the causes of disabled peoples’ economic and social exclusion because it does little to combat existing exclusionary market and welfare structures. Emphasis on the disabled individual, rather than social structures, means that the inclusion process will fall most squarely on the shoulders of disabled people and Personal Advisors. Riddell, Banks and Wilson (2002) argue that, as a predominantly supply-side measure geared towards fitting disabled people into the labour market with relatively little support, the Employment Service’s Work Preparation Programme in Scotland is achieving modest gains and that better outcomes might be achieved if additional and ongoing support were available for disabled people with higher support needs.

2.83 A key consideration found in a national survey (Loumidid et al 2001) of Incapacity Benefit claimants was the availability of suitable work. Half of the respondents stressed that this meant work that was not physical, not stressful and flexible (see following section). Respondents were also keen to know that they could return to their original benefit if the job

did not work out. A sizeable proportion said that transport to and from work would make it easier for them to take up paid employment whilst 42% stated that they felt unable to work. The report also found that fewer than half of those surveyed expressed an interest in help to prepare them for work (46%), find training (41%), find paid work (47%), help them try out a job (46%) or support them to stay in a job (46%). Thus Burchardt (2000) stressed that the New Deal for Disabled People pilots on job retention would need to recognise that barriers to continuing employment, for people who acquire impairments, occur at and beyond the workplace, as well as at an individual level. Irving et al (2004), in developing a framework for vocational rehabilitation, suggest that early intervention, a person centred approach and a case management approach should be common principles.

2.84 Employers' management of long-term sickness was the subject of a study by Nice and Thornton (2004) who found that employers considered sickness absence a problem because of difficulties providing cover. They found that the use of services for rehabilitation was not strongly evident but that in general employers were willing to consider and make adjustments or adaptations to employees' working conditions and the workplace.

2.85 Roberts et al (2004) found that many (especially small) employers, and those who had never employed a disabled person, lacked knowledge both about disability and about the DDA. The Act sets out to tackle discrimination but only 4 cases have been won at employment tribunals in Scotland since the passing of the legislation. Gooding (2000) argues that the DDA has had a limited impact, and that the response of employers has been largely disappointing. Thus more proactive measures need to be taken with an explicit emphasis on achieving substantive rather than formal equality. It should be pointed out that the studies reviewed here were all conducted before October 2004, when new employment provisions, affecting businesses with less than 15 employees, came into force under the Disability Discrimination Act 1995.

#### *Widening access to work*

2.86 Work must pay, and be accessible for disabled people. Their specific needs in respect of medical and vocational rehabilitation, reorientation or training if the nature of their impairment requires a change of occupation and any needed equipment or structures to facilitate access to work must therefore be addressed. Such barriers include the attitudinal and organisational hurdles currently keeping disabled people outside the labour market (OECD 2003).

2.87 Ill-conceived training programmes are not helpful in making the transition to work for young disabled people and supported employment may well have more to offer in terms of opening the door to financial independence (Riddell 1998b). Inadequate funding is also cited as a reason that the Government's Access to Work scheme, which is of vital importance in improving the employment opportunities of disabled people, is not currently providing the support required by many (Disability Employment Coalition 2004).

2.88 A number of studies note that disabled people and young adults are not included in the work and employment related decisions made about them by professionals (Stalker 2002; Social Care Institute for Excellence 2004) and suggest that people with complex needs must have a choice and feel included in the process of getting and keeping a job (Weston 2002a).

2.89 Inverness Access Committee (2003) also recommends that networking opportunities should be encouraged for potentially employable or newly disabled people and that disability employment/benefit advisors should be situated in hospitals, residential homes and local housing organisations.

2.90 There is a need for government to counter the myths and misconceptions employers hold about disability and the requirements of the DDA. There is also potential for a more general education and awareness campaign about the breadth of disability (Roberts et al 2004).

2.91 Policies also often focus on barriers specific to impairment. These are important, argues Burchardt, but do not exhaust the disadvantages faced by disabled people, a high proportion of whom lack a connection with the labour market, come from a lower social class background and have fewer educational qualifications.

### **Gaps in the evidence base**

2.92 There is a need for research on:

- the impact of the employment provisions of the Disability Discrimination Act 1995 in relation to businesses with less than 15 employees, which came into effect in October 2004.
- there is a need for good quality qualitative studies to supplement quantitative research, especially about disabled peoples' experiences in work, employers' perceptions, stereotypes and assumptions, quality of work, wages and glass ceilings (Samuel 2001).
- ongoing research by Burchardt on the aspirations and outcomes of disabled people's employment, due in 2005, should help to plug the identified gap in the literature on disabled people's attitudes to working, but not about attitudes to employing disabled people (Smith and Twomey 2002).
- Riddell et al (2005), in their recently published report to the Scottish Executive, identify a number of areas requiring further research, including Jobcentre Plus programme evaluations, the impact of the National Minimum Wage and variations in disabled people's employment experiences according to impairment, age, gender, ethnicity, social class background and geographic location.



## SECTION 6: BENEFITS

### Publications profile

2.93 Notwithstanding devolution in Scotland, social security benefits remain a national concern in the UK. This is reflected in the fact that much of the research discussed here applies to the UK. Some payments (which are not benefits) are administered by local authorities, notably direct payments. These are discussed in Section 10 on social care.

#### **This section is based on 30 publications**

- 27 reports
- 2 journal articles
- 1 conference proceedings

#### *Type of evidence:*

- 5 policy/literature reviews
- 1 report of conference proceedings
- 19 studies, 11 qualitative, 2 quantitative, 6 mixed methods
- 3 national statistics
- 1 service review
- 1 theoretical paper

#### *Location of research*

- 9 Scotland
- 18 UK
- 2 England
- 1 international

*Disabled people's views included in 17 publications*

### Summary of main findings

#### *Statistics*

2.94 In the Disability Survey 1996/7, households containing at least one disabled adult had a total income that was 20-30% lower than all households. This was because, in general, income from work was much lower for such households and this was true across all household types. Social Focus (Scottish Executive 2004b) reports Scottish Household Survey results relating to receipt of benefits: 65% of claimants of at least one key benefit in August 2003 were from the 'sick/disabled' client group and this group of claimants represented 11% of the working age population.

2.95 As indicated in the previous section, there are complex links between disability, socio-economic status, employment and benefit receipt. Burchardt (2003) notes for example that people in the poorest fifth of the income distribution are two and a half times more likely to acquire impairment during a year than those in the top fifth and that the effect on employment status, and thus benefit receipt, varies widely by severity of impairment.

### *Financial exclusion*

2.96 There is wide variation in the financial position of disabled people depending on what benefits they have knowledge of, apply for, and receive. However, Burchardt (2000) notes that half of all disabled people have incomes below half the general population mean (often taken as an indicator of poverty) after making an adjustment for extra costs. Even without adjustment, two in five were found to be in poverty (Burchardt 2000). Variation in the financial position of disabled people will also be compounded by the role that local authorities take in relation to the administration of direct payments.

2.97 Excluded from employment (see Section 5), disabled people are often reliant on social security benefits. Access to financial resources was found to be a key, though not the sole, component in whether people felt able to overcome (multiple) disadvantage (Molloy et al 2003). Research has consistently demonstrated however, that benefit rates for disabled people in the UK are inadequate for their needs. As noted by Smith, Middleton, Ashton-Brooks, Cox, Dobson with Reith (2004), disabled people face extra costs in most areas of everyday life, whether in respect of major expenses for equipment essential for independence or in regard to higher expenses for food, clothing, utilities and recreation. Yet, as the authors demonstrate, the weekly income of disabled people who are solely reliant on benefits is approximately £200 below the amount required to ensure an acceptable, equitable standard of life. RNIB (2000) note for example that communication for those with a visual impairment incurs very high costs (use of phone, reading and study materials, for example).

2.98 Research on issues relating to debt and disability (Grant 1995) found that most respondents (who were in receipt of social security benefits) had had to cut back on expenditure related to their impairment, such as short term care, the use of accessible transport or food for special diets, as debt repayments reduced their disposable income. Carers also cut back on their own quality of life in order to meet the needs of the disabled person. Some interviewees had received independent money advice and had described it as a turning point in their lives, however, even debt advice services aimed specifically at disabled people were found to not always take account of the differing needs of people with different impairments.

2.99 The only specific mention of the need for financial support of people with early onset dementia is from Alzheimer Scotland Action on Dementia (2003) who argues that, if needed, free personal care should be extended to people under 65. Financial implications of early onset dementia have been considered, for example loss of earnings and loss of pension in the future, alongside continuing financial pressures of education for children and mortgage payments (Alzheimer Scotland Action on Dementia 2003, SNAP 2000, Robertson 1996). While this discussion does not specifically refer to benefits, the financial impacts of loss of earnings and pensions will influence the need for benefits.

### *Complexity of the system*

2.100 The UK has a complex system of 'poorly branded' social security benefits for disabled people and beneficiaries are often confused as to what benefit they actually receive (Hedges and Sykes 2001). Such issues may be particularly salient for disabled non-English speaking claimants. As noted already in this report, Disability Alliance (2004) argues that the benefits system disadvantages such claimants because of their ethnicity, language and literacy

skills, social isolation, cultural attributes, and in the case of Asian women, gender. Such factors make the system inaccessible to these potential claimants and they argue that the Department for Work and Pensions' (DWP) special support arrangements for disabled and carer ethnic minority claimants (translating, interpreting, helplines, home visiting and outreach) are patchy in extent, of variable quality and poorly publicised. The authors argue that the DWP assumes that it can rely on an under-funded, under-resourced and overstretched voluntary sector to provide the practical help that benefit claimants need to process their applications. Indeed, the SDEF commented that there is a general feeling that the benefits system appears to be, based on "How can I deny you benefit?" rather than assisting disabled people in providing support. However the Disability Alliance (2004) makes a number of suggestions for good practice in this area. In developing strategies to overcome ignorance about, and non-take up of, benefits the authors argue that the DWP needs to run high profile promotions via both mainstream and ethnic minority media. For ethnic minority communities where women may be particularly isolated, the DWP should develop a double pronged strategy – directly targeting women's social networks and telling men about their female relatives' possible entitlement.

### *Inflexibility*

2.101 Several studies point out that benefit rules need to be sufficiently flexible to accommodate hospital stays (Disability Alliance 2003), fluctuating conditions (particularly associated with mental health problems and some degenerative diseases) and varying patterns of work (Burchardt 2000; O'Bryan et al 2000).

### *Exclusion from employment*

2.102 Steps have been taken in the UK to address the uncertainties and financial disincentives which disabled people moving into work and off benefit might face (see for example Kestenbaum and Cava 1998). A number of 'work incentives' have been introduced by the Government which aim to increase the choices available to disabled people claiming Incapacity Benefit about whether and how to work, enable people to try work without financial risks or penalties and to 'make work pay'. Such measures can be related to a significant trend in (especially certain areas of) the UK over the past 20 years - the rise in the number of disability benefit recipients and the increased duration of their claims (Berthoud 1998) and some Scotland specific research has focused on reducing the risk of future claimants ending up on long-term sickness benefits (McCormack 2000). Since 1995 there has been a series of reforms to Incapacity (previously Invalidity) Benefit, when the 'own occupation test' was replaced by the more stringent 'all work test'. Evidence highlights that there were differences between those who left IB voluntarily and those who were disallowed under the stricter rules as to their later employment positions (Dorsett et al 1998). More recent reforms have included the New Deal for Disabled People (see section on employment) and a focus on capabilities within medical assessments (see Legard et al 2002). Research evaluating the most recent Incapacity Benefit reforms (Dickens et al 2004) found that, whilst some customers were 'pleasantly surprised' by the range of support on offer when they attended a Work Focused Interview, others felt it was insensitive that they had been asked to attend at all. O'Bryan (2000) calls for a change in the culture of the Employment Service and the need to establish effective welfare rights advice for disabled people.

## SECTION 7: HOUSING

### Publications profile

2.103 This section is based on research that is predominantly Scottish in focus. Much of the UK and English research included is used to highlight examples of good practice by housing builders and providers.

#### **This section is based on 26 publications:**

- 2 report of conference proceedings
- 16 reports
- 4 journal papers
- 4 periodical

#### ***Type of evidence:***

- 3 policy and literature reviews
- 14 research studies, 8 using qualitative methods, 3 using a mix of qualitative and quantitative methods, 3 pilot/ feasibility studies
- 5 service review
- 2 national statistics publications
- 1 conference proceedings
- 1 discussion paper

#### ***Location of research***

- 18 in Scotland
- 6 in the UK
- 2 England

*Disabled people's perspectives included in 13 publications*

### Summary of main findings

#### *Statistics*

2.104 Statistics on special needs housing for disabled people (Scottish Executive 2004b) record a steady increase in 'wheelchair housing' and 'ambulant disabled' housing since 1980. Current levels are around 4,000 'wheelchair' and 16,000 'ambulant disabled' houses. Provision varies greatly between local authorities. National statistics on the numbers in receipt of help from Supporting People budgets are not available. The Scottish Household Condition Survey 2002 (Communities Scotland 2003) gives an overview of levels of disrepair in Scotland's housing stock and a summary of maintenance and repairs completed and required. This includes some data on adaptations (see section 12).

## *Overview*

2.105 Access to suitable housing is a key component to disabled people achieving independence (Palmer and Bonnar 1995). However, Laurie and Macfarlane (1995) noted that disabled people were not involved in planning processes for housing and community care in any systematic way. Where they were involved, this was found to be at the lowest tier and on a single impairment basis. Similarly, the quality of information held by local authorities on the housing needs of disabled people was poor and rarely took account of the expressed views of disabled people about their needs. The authors conclude that improvements would be unlikely whilst purchasers and providers viewed disability as having a medical rather than a social basis.

2.106 Grewal et al (2004) highlight the difficulties faced by disabled people in making the transition between homes. Problems may arise either because people do not get the services they need, including a new need not being met or losing an existing service, or else due to delays in getting the services they need. In relation to rural Scotland, Field and Oldman (1997) found that there was very little knowledge about the housing and care needs of rural community care clients. Needs in such areas may be less obvious than in urban areas because of a greater tolerance of poor housing conditions and because local choice of provision is restricted. The research identified a number of small scale, locally based, surveys in Sutherland and Dumfries and Galloway which have adopted a comprehensive approach to community care needs. The Personal Housing Plan developed in Skye is also cited.

## *Tenure*

2.107 Disabled people are twice as likely to live in the social rented sector as households overall. The main barriers faced by disabled people when trying to access suitable housing are market barriers relating to the right type of housing in the right locations and financial barriers relating to their relatively low income (see the previous section on benefits) (DTZ Pidea Consulting 2004).

## *Aspirations*

2.108 In a study exploring the housing aspirations of young disabled people in Scotland, Dean (2003) found that the principle barrier identified by young people in accessing suitable good housing was a lack of information concerning housing choices. This is important given that their desires and actions were shaped by their beliefs about housing, which were often inaccurate or partial. The research further found that in contrast to the underlying policy assumption that young disabled people leave home in a planned way because they are ready to do so and that they will continue to live in their first home for a long period of time, if not for life, those who had actually left home were found to have taken one of three 'pathways'.

2.109 MacDonald (1995) argues that people with 'special needs' do not want to give up their home, but can find the practicalities of looking after it difficult. The research suggests that an independent tenancy with support visits may be the answer, and a typical arrangement in the research carried out in central Scotland was one where a support worker employed directly by a housing association visited tenants each week. The research found that it was

common that people's knowledge about their own position was limited. For example, some did not know how the service they received was funded, how much they paid for it out of their own benefit or what entitlement they actually had to support services. In a further study by McDonald et al (1998) of floating support for three different client groups in Scotland, the researchers found that the services provided a range of practical, emotional and moral support and that there was widespread satisfaction with the perceived responsiveness and flexibility of services, apart from home help services for disabled people – which were not flexible enough to meet their needs. Again however, there was little evidence of user choice and people had little understanding of their entitlement to support or how it was funded.

### *Technology*

2.110 There has been a growing number of studies on the development and use of technology in the home to assist disabled (and other) people in recent years (Dewsbury et al 2004, Gann et al 1999). Dewsbury et al (2004) point out that as housing design moves away from the 'special needs' approach to a more universal and inclusive form of design, the problem still exists of how to ensure that real needs are met. Heywood (2004) argues that there is a danger of underestimating the complexity and range of human need when considering disabled peoples' housing needs. Most participants in their study were very positive about adaptations carried out in their homes. However, where such work had been carried out in a disempowering way or at the cost of destroying valued aspects of the home or family relationships, they were not perceived to be beneficial. The author concludes that the Winfield model of need would effectively lead to better provision than the traditional functional model.

### *Affordability*

2.111 There can be barriers to work because of housing, or at least tensions between housing, benefits, employment and health policies that encourage people towards dependence rather than independence (Riddell and Banks 2001). Research by Griffiths (2000) suggested that if the Supporting People Programme is to promote independent living, then the link between registered accommodation and its financial consequences needs to be broken and that charges should be coordinated in a way that ensures users' disposable income is not pushed below acceptable levels.

### *Extending accessibility*

2.112 McKenzie (2002) argues that the needs of wheelchair users are going unmet because housing providers are not building appropriate accommodation. Currently there is an independent review of NHS wheelchair services which should go some way towards highlighting the mobility issues of both service users and carers.

2.113 Because of the high levels of confusion and ignorance over what housing choices might be available, Dean (2003) suggests that parents and young disabled people should be provided with accessible information that could inform their decisions. This needs to be available before the young person is of an age to leave home, assist them to think about what would be good housing for them, explain how to find out about local options, provide details

about sources of information and advocacy, consider all options (living with parents, alone, with friends and so on) and cover all tenure options.

2.114 MacDonald (1995) argues that cost funding arrangements can make it difficult to provide a truly flexible and ‘needs-led’ service. Similarly, Lomax (1999) identifies ‘financial pressures’ as a key element in producing the gap between the expressed aims and intentions of providers and managers towards the occupants of supported housing and actual housing management practices. The author contends that the success of community care policies crucially depends on appropriate funding and housing management practices. It is reported that, in comparison to England, the funding mechanisms for housing assistance for disabled people in Scotland are inferior: there are fewer options, Home Improvement Grants (HIG) are not mandatory and the eligible maximum grant is lower. Research by DTZ Pidea Consulting (2004) recommends a new financial assistance mechanism to help overcome market and financial barriers which should effectively work alongside the HIG scheme so that houses are adapted as well as being available.

### **Good practice**

2.115 Field and Oldman (1997) make a number of recommendations for good practice arising from their research:

- continuing the established policy of positive discrimination in housing resource allocations in favour of rural areas, given that good quality, affordable housing is essential to the successful implementation of community care policies
- the expansion of the care and repair model, which is well established in rural areas, to a range of user groups, and going beyond its home improvement role by acting as a base for other services
- assessing the housing needs of community care users at local level since authority-wide surveys do not uncover local and diverse rural need
- given its potential for community care, the Personal Housing Plan methodology pioneered on the Isle of Skye should be replicated
- expansion of intensive housing management services, particularly dispersed or floating housing support, in rural areas
- information technology, despite its high costs, has a key role in the provision of information and advice to dispersed communities.

2.116 In relation to people with early onset dementia:

- an example of an innovative service is an independent supported living house in Newcastle which aimed to respond to the changing needs of residents and provide physical comfort, personal care, security, management of mood/behaviour and the maximisation of pleasure and achievement. Cantley and Smith’s (2000) independent evaluation of this service found that key elements of good care were use of observation, negotiation, individual responses and encouragement by staff. Good quality care was achieved partly because the staff and family members were committed to the goals of the project.

2.117 In relation to people with visual impairment:

- In a survey of access to housing information and advice for people with visual impairment, Scottish Homes (1999a) found that effective services tailored their approach to individual needs and circumstances and focused on providing services directly to the visually impaired client without using intermediaries. The research found that whilst physical access to agencies varies, it is generally improving.

2.118 **Gaps in the evidence base**

- Samuel (2001) identifies the following research priorities: mapping available and accessible housing, more research on the housing needs and aspirations of disabled people, the options available and evaluation (including cost evaluation) of these options.
- research to assess and promote mainstreaming in housing, beginning with housing design and taking the research right through to housing allocation (Samuel 2001).
- in a study on tenancy rights for community care client groups in supported accommodation in Scotland, Edgar and Muirhead (1997) noted that little was known about the preferences people may have had regarding different forms of living arrangements or the impact of tenancy agreements on their ability to exercise choice, preference and sovereignty.



## SECTION 8: TRANSPORT

### Publications profile

2.119 This section draws mainly on the rather limited Scottish research that has been carried out in the area of transport. Less evidence was found about transport than any other key topic in this report. As part of our consultation exercise with SDEF's member organisations, The Tweeddale Access Panel expressed surprise about the apparent paucity of research on transport. They highlighted disabled people's concern about the reliability, accessibility and affordability of public transport, factors which 'make(s) most disabled people unable to use public transport, which in rural areas means exclusion and isolation' (personal communication, Tweeddale Access Panel).

#### **This section is based on 8 publications:**

- 8 reports

#### ***Type of evidence:***

- 1 baseline review
- 1 literature/policy review
- 5 studies; 3 using qualitative methods, 2 using qualitative and quantitative methods
- 1 national statistics publications

#### ***Location of research***

- 7 in Scotland
- 1 in UK

*Disabled people's perspectives included in 6 publications*

### Summary of main findings

#### *Statistics*

2.120 The Scottish Household Survey includes questions about access to private and public transport and findings are presented in Social Focus on Disability (Scottish Executive 2004b). Disabled adults are less likely than other adults to hold a full driver's licence and households with at least one disabled adult are less likely than other households to have access to a car. Forty seven per cent of all adults with an impairment do not use their local bus service for a wide range of reasons (some of which are discussed further below).

#### *Inaccessibility of public transport*

2.121 Of the 12% of the Scottish population estimated to have some form of impairment, 5% are likely to experience a significant difficulty in using public transport and the remainder may experience some difficulty (Reid Howie Associates 1999). Recent research in this area, which has charted the progress made in transport provision for disabled people in Scotland since 1998, notes the improvements that have taken place in the accessibility of public

transport vehicles and infrastructure, for example, the introduction of buses with low floors, more accessible trains on many routes and improvements to Scotland's airports (Reid Howie 2004). Despite the establishment of the Mobility and Access Committee for Scotland (MACS) and the progressive implementation of the Disability Discrimination Act (1995) however, research illustrates that the pace of change has, overall, been slow and patchy. The SDEF commented that 'Special Needs Transport' should be provided in all local council areas, in partnership with a voluntary organisation.

### *Geographic diversity*

2.122 Geographically, provision remains uneven and hence there are still areas of Scotland where there is little public transport that is accessible to many disabled people. Thus only 15% of Scotland's bus fleet had a low floor and some strategically important bus stations were found to be inaccessible to disabled people (Reid Howie 1999). This calls for an integrated and co-ordinated public transport policy at both the national and local level. 'Joined up policy' and inter-agency working (Riddell and Banks 2001) are thus necessary to tackle 'transport related social exclusion' (Hine and Mitchell 2001).

2.123 The lack of accessible transport provision in Scotland is further shown to impact on disabled people's decisions to use public transport. For example, Reid Howie Associates (2004) note that a considerable source of stress for disabled people is that of 'uncertainty' regarding the accessibility of the different forms of transport which might be required to complete successive legs of a journey: whether the bus will have a low floor; the train be accessible; a taxi available and whether assistance arranged in advance of a journey will actually be available when needed. Such uncertainty can effectively constitute a disincentive to travel for disabled people.

### *Financial Barriers*

2.124 A further and significant barrier identified in the use of public transport for disabled people is that of financial cost. The costs of taxis, for example, were found to be relatively high in all areas of Scotland, most especially where no concessionary fare schemes operated. In the island areas of Scotland, the costs of flights and ferries were also found to be an issue raised by disabled people.

### *Disabled people's views*

2.125 Disabled people surveyed by Reid Howie (2004) identified a number of priorities for provision. They stressed the importance of consistent, dependable, affordable (especially in regard to taxis) and more accessible public transport. The attitudes and approach of public transport staff and other customers were further thought not to be as appropriate or as positive as they might be. This finding echoes research by the Edinburgh and East of Scotland Deaf Society (2001) which highlighted that communication between young Deaf people and staff on public transport was difficult and concluded that staff should be trained accordingly. Consultation between disabled people and transport providers was thought to be the most effective way of ensuring that services were appropriate to the needs of disabled people in Scotland.

### *Social exclusion*

2.126 Much of the research reviewed in this area highlights that transport related social exclusion affects disabled people's opportunities for participating in the labour market and accessing social and leisure facilities. This is the subject of a report by Capability Scotland (2004) which highlights the ways in which inappropriate public provision can disadvantage disabled people 'in every area of life'. The author argues that many of the improvements disabled people are looking for in transport provision would also benefit other travellers and various useful recommendations for change are made.

### **Good Practice**

2.127 The following recommendations for good practice in action are made in Capability Scotland's (2004) report:

- providing dedicated information services about the accessibility of public transport
- ensuring that future transport regulations do not allow taxi companies to discriminate against disabled people
- ensuring all disabled people are included in concessionary schemes
- ensuring concessionary schemes take account of disabled people's additional living costs
- steps to increase disabled people's confidence in using public transport.

### **Gaps in the evidence base**

2.128 As noted above, our consultation exercise highlighted transport as a topic which some disabled people consider requires more research - and action. Similarly, Riddell and Banks (2001) proposed further and more detailed research on the impact of DDA on transport provision in Scotland. Capability Scotland identify a need for research into the times, destinations, routes and types of vehicle required to satisfy disabled people's transport needs.

## SECTION 9: GOODS, FACILITIES AND SERVICES

2.129 There has been little research specific to Scotland dealing with goods, facilities and services for disabled people, although UK wide studies have been carried out by the Department of Work and Pensions and the Disability Rights Commission. A number of smaller scale studies have focused on young disabled people's access to goods, facilities and services in Scotland. We have excluded research about social care and health services which are discussed in the following two sections.

### **There are 18 publications in this section:**

- 10 reports
- 4 journal papers
- 4 web publications

### ***Type of evidence***

- 11 research studies, 6 using qualitative methods, 3 using quantitative methods and 2 using a mix of methods
- 2 literature reviews
- 2 service reviews
- 1 conference proceedings
- 2 national statistics publications

### ***Geographical location***

- 8 Scotland
- 9 UK
- 1 England

*Disabled people's views included in 12 publications*

## **Findings**

### *Statistics*

2.130 Expenditure on everyday items is significantly higher for many disabled people – a factor which is likely to affect access to and use of goods, facilities and services. The DSS Disability Survey found that significant proportions of disabled people reported spending more than non-disabled people on a wide range of goods and services including laundry, food, transport and heating. The likelihood of spending more on these items was higher for people with more severe impairments. For all the items included, the proportion of people who received extra financial help for the particular expense was lower than the proportion who said they incurred extra expense. For blind and visually impaired people, communication facilities, such as use of the telephone, reading and study materials, also incur considerable extra costs and this is analysed in the RNIB publication on the costs of blindness.

### *Impact of the Disability Discrimination Act 1995*

2.131 The DDA sets out rights for disabled people in five areas including access to goods, facilities and services. Under the Act, discrimination occurs when a disabled person is treated less favourably than others because of impairment and this treatment cannot be justified. It also occurs when an organisation fails to make a reasonable adjustment. This refers to agencies' duty to provide additional support or alter the way they deliver services or run their business, in order to accommodate a disabled person. Since October 2004, service providers - 'from the largest public sector organisation to the smallest corner shop' (DRC 2004d) - have been responsible for making 'reasonable physical adjustments' to their premises to ensure disabled people are not discriminated against.

2.132 A study commissioned by the DWP investigating awareness of the DDA among employers and service providers found that, due to a narrow interpretation of 'disability', 'adjustments' made were largely limited to physical adaptations, with many providers wrongly assuming their services were then fully accessible to all customers (Stuart et al 2002). However the DRC (2002) points out that access to goods and services has other dimensions, such as staff attitudes and awareness, methods of communication, and policies and procedures such as information provision. Stuart et al found that, while general awareness of the Act was high among service providers, few had detailed knowledge and understanding of it. Nearly a third reported they had no disabled customers over the last 12 months or did not know if they had. Many providers were unaware of the potential needs of disabled customers and did not believe any changes were needed to their existing services. The authors concluded that attention should focus on raising awareness, knowledge and understanding among small and medium sized service providers. A further study by the DRC (2003) canvasses the views and experiences of 1004 disabled people, aged 16 and over, in Scotland, relating to access to goods and services under part III of the DDA. Sixty-two per cent felt that not enough was being done to ensure disabled people could purchase goods or services in the same ways as non disabled people. Fifty-one per cent reported that heavy doors caused the most difficulty while 48% cited steps at the entrance to buildings. There was considerable regional variation, however, with those living in the West of Scotland finding access more problematic than those in the North. The DRC (2004b) also commissioned an independent research organisation to conduct a telephone survey of providers of goods, facilities and services in Scotland, as part of its Open 4 All campaign to raise awareness of their new duties, under Part III of the Act, relating to access requirements. Eighty seven per cent of businesses were aware of the impending changes but most had not made any changes to enable access.

2.133 Another survey commissioned by the DWP (Grewal et al 2002) explored attitudes towards and experiences of disabled people across the UK. One in five of the 2064 respondents had experienced difficulties accessing goods and services, which the authors describe as 'relating directly to their impairment'. Only about a quarter had complained to the service provider and two out of ten were satisfied with the response. Gooding (2000) describes service providers' response to the DDA as 'largely disappointing', arguing that more proactive measures are needed, with an emphasis on bringing about substantive rather than formal equality.

2.134 The findings of these large scale quantitative studies are echoed and to some extent illuminated in a number of smaller qualitative studies. The range of goods, facilities and services identified as hard to access include mainstream social, cultural and leisure facilities,

public transport, high street goods and services, financial services, telecommunications and adult guidance services. Barriers identified as inhibiting access include:

- lack of understanding among staff, and negative attitudes towards disabled people's needs
- the nature of the built environment
- poor information provision, including insufficient material translated into community languages; not enough interpreters
- high costs and low level of personal income among disabled people
- poor presentation of goods in terms of labelling, signing and audible messages
- failure to use available technologies.

2.135 It is not clear why a number of studies in this area have focused particularly on young disabled adults: presumably many of these barriers would impact on middle aged and older disabled people as well. However, hanging out in the 'right' places such as shopping centres, pubs and clubs, and being able to buy the latest clothes, music, and so on is an important part of youth culture, so this may explain the attention to younger people. Hughes (2005) argues that the curtailment of leisure and consumption opportunities among young disabled people is a major social disadvantage. MacDonald (1996), exploring young disabled people's experiences as consumers, concludes that they led more restricted lives than their non-disabled counterparts. They made less use of shops and leisure facilities, had less spending money and were also less likely to have access to their own money. Yet at the same time many were very articulate, eager to be independent and unwilling to accept obstacles. They wanted to be treated on equal terms with non disabled people and they wanted inclusive services. Attention has also been drawn to the particular barriers in accessing goods and services experienced by disabled people from Black and minority ethnic communities, Deaf people, and lesbian and gay disabled people.

### **Good Practice**

2.136 The DRC (2002) Policy Statement on Access to Goods and Services sets out the following points, among others:

- access for disabled people should be considered from the outset in the design of manufactured products
- access should be a mainstream part of the service, not a special facility
- access to goods and services goes well beyond physical access to a range of considerations, for example; providers of goods and services should provide suitable communication support for people using British Sign Language.

2.137 Hogg and Cavet (1995) discuss a range of good practice initiatives and activities in leisure provision for people with profound multiple impairment and offer guidance on running and developing training courses for parents, carers and professionals. Similarly, Lambe and Hogg (2000) bring together information about innovative work in creative arts with this user group.

## **Gaps in the evidence base**

2.138 It has been suggested that more research is needed as follows:

- action research - the Scottish Executive should produce guidelines for voluntary and public sector provision regarding 'national standards' of equality. These standards should be monitored and evaluated and good practice mapped
- evaluation of the new provisions of the DDA which came into force in October 2004 affecting providers of goods, facilities and services.

## SECTION 10: SOCIAL CARE – NEEDS AND SERVICES

2.139 This section comprises far more publications than any other. It covers research on a wide range of areas, including direct payments since these are provided by local authority social work departments and the majority of studies on early onset dementia. Again, most research in the social care field relates to particular groups or specific services with few broader based Scottish studies. The most recent overview of social care services for disabled people in Scotland was published nearly ten years ago.

### **This section comprises 57 publications:**

- 33 reports
- 12 journal papers
- 3 conference abstracts
- 2 briefings papers
- 5 web publications
- 2 works in progress

### ***Type of evidence***

- 37 research studies, 6 using quantitative methods, 18 using qualitative methods and 13 using mixed methods
- 11 research/ policy reviews
- 5 service reviews
- 3 sets national statistics
- 1 conference proceedings

### ***Geographical location***

- 27 Scotland
- 25 UK
- 3 England
- 2 International

*Disabled people's views given in 28 studies*

## **Summary of main findings**

### *National statistics*

2.140 According to the Audit Commission's latest published figures there were 49,756 people aged 18-64 with physical disabilities receiving a community care service in 2003-4 (see <http://www.audit.acotland.gov.uk>). This represented 15.8 per 1,000 of this age group in the population, higher than in the previous two years. According to the SHS (2001/2), 24% of disabled adults aged 16-54 and 19% aged 55-64 require regular help or care. The 1996/7 Disability Survey presents detailed findings on the frequency of use of a range of social services and the types of task with which help was needed by age (Grundy et al 1999).

2.141 The Scottish Community Care Statistics 2002 provides the most recent information on service levels for people with physical impairments. In 2002 11% of 'physically disabled' home care clients were aged 18-64. For individual local authorities, this proportion ranged from 6% to 28% and the proportion of people with physical impairments in the population



receiving home care also varied significantly. However, as the Scottish Community Care Statistics report points out, such differences may be due more to the way that councils classify clients than to real differences in service provision. Community Care statistics (Scottish Executive 2004c) illustrate that in the period 1998-2002 the number of home care clients with physical impairment has declined, with the 16-64 age group making up 11% of the total. The Audit Commission also collects information annually from Councils about the provision of short breaks (respite care) to adults aged 18-64. However, separate information is not available for people with physical/sensory impairments nor those with early onset dementia. The Scotland results for 2003/04 were as follows:

Performance Indicator	rate per 1,000 pop aged 18-64
residential respite care bed nights provided per 1000 adults	39.7
respite care hours provided at home per 1,000 adults	171.5
hours of day service	451.2
nights provided by other overnight services	1.9

Figures since 2001/02 indicate an increase in the amount of respite care provided to younger adults at home.

2.142 There were 45 day centres for people with physical impairments in 2002, 10 of which were in Highland region and 8 in Glasgow. Nineteen of the 32 councils provide such day centres.

2.143 After a slow start, receipt of direct payments for care has increased from 207 in 2001 to 912 in 2004. In 2004, 450 direct payment recipients had physical impairments and were aged under 65 (Scottish Executive Direct Payments Statistics Release 2004).

2.144 Fifty care homes, with a total of 851 places, provided for physically impaired people in 2004. Only one of these care homes is run by a local authority. The voluntary sector is responsible for 42 of the homes and the private sector 7. A minority of residents are aged 65+ (17% in 2003). There has been a decrease of 11.7% in the number of care home places since 2001. However 14 of the 20 care homes which closed during that period de-registered with the Care Commission to become a Housing Support service (Scottish Executive Statistics Release, March 2004, quoted in DRC 2005).

#### *Overview of social care provision*

2.145 In 1994, Stalker and Reddish were commissioned by The Scottish Office to conduct an overview of health and social care services to disabled people in Scotland. Their report was published in 1996. It involved interviews with local authorities, health boards and voluntary agencies, visits to prominent and 'good practice' services, and discussions with service users and organisations of disabled people. The authors pointed out that for many disabled people health and social work services are not the main priority: rather, employment, income levels, transport, access and housing were often the key concerns. Some disabled people felt they should not have to become 'service users' or 'social work clients' in order to gain the necessary support to lead an ordinary life. Some aspects of the picture have changed considerably since 1996, with the implementation of direct payments, anti-discrimination

legislation, more widespread consultation and involvement in service planning and delivery and the Joint Future Agenda.

2.146 Nevertheless, some of the 1996 findings may still have resonance today. Stalker and Reddish found that social care services to disabled people were a ‘Cinderella service’, with other user groups generally taking priority. Overall, development was piecemeal and patchy, at both policy and service level, between and sometimes within local authorities. Attitudes to services in rural parts of Scotland were influenced by a range of historical, cultural and demographic factors which have considerable impact on people’s daily lives, a factor which, in the view of some disabled people living in the Highlands, is not always appreciated by policy makers in the central belt.

2.147 A more recent ‘baseline study’ of policy, official statistics and research relating to disabled people in Scotland (Riddell and Banks 2001) notes that much social care policy is impairment –based, with attention being paid to specific groups sequentially (as reflected for example in the development of a framework for services to people with mental health problems, followed by the recent review of services to people with learning disabilities). The authors note there has been no recent national review of provision for people with physical impairments. In their review of social care research, Riddell and Banks found relatively little Scottish material.

2.148 In a review of assessment and care management for all community care groups in Scotland, Stalker and Campbell (2002) found great diversity of views among local authorities regarding the objectives of care management and significant variation in practice between and sometimes within authorities. The largest client group involved in care management was older people, followed by those with physical impairment and those with dementia. Most care managers had limited spending authority, with half reporting that there was insufficient good quality local provision to offer users real choices. About two thirds also faced restrictions limiting access to a range of service providers. However, they claimed greater success supporting disabled people than other users, mainly because alternative sources of funding were available, such as resource transfer, direct payments and independent living fund monies.

2.149 South of the border, The Prime Minister’s Strategy Unit has been developing a ‘vision’ to remove barriers and improve the life chances of disabled people. Its report (2005) considers emerging key policy questions in various areas, acknowledging that disabled people’s social care needs are currently responded to on a piecemeal basis. The report suggests that central government has a part to play in setting out broad frameworks and minimum standards, but that local partnerships also have a key role.

2.150 A different kind of overview is offered in a survey of public attitudes to community care in Scotland (Curtice and Petch 2002). Respondents were strongly in favour of individuals with support needs living in the community rather than care homes. The majority thought that support needs should be met by paid workers, funded by government.

2.151 The SDEF suggested that, overall, there is a great deal of information available from both statutory and voluntary bodies about social care and there is an identifiable demand for that information but what is absent is the mechanism to bring these two together in an easy and efficient way.

### *Choice and control*

2.152 A recurring theme in this research is the importance of disabled people exercising choice and control in relation to their support. An action research project by Cole et al (2000) aimed to develop new lifestyles for disabled people living in a voluntary sector care home, using person centred planning to enable individuals to realise 'more of their hopes, dreams and ambitions'. Focusing on activities people wanted to do, over a third reduced their use of day services while for service providers, 17 days of service per week were freed up. Many people wanted to have part time paid work: this entailed intensive long term support. The project concluded that service reorganisation was required to help people achieve their goals, particularly moving away from congregated buildings-based residential and day services. A reminder of just how far there is to go for some people comes from a study of 75 nursing homes in Glasgow: 92 adults, aged 16 - 64, were placed in these homes. Grover (1996) suggests that 'intentional communities' offer a 'third way' between formal 'professionalised' and family care models, offering interdependence, with disabled people living alongside non-disabled residents. The former are involved in a wider range of community activities than is available in 'professionalized' care settings. Forty-seven such communities are identified in the UK.

2.153 The opportunity to exercise choice and control over their support arrangements, and thus over other aspects of their lives, was identified as the most significant benefit of direct payments by 143 recipients across Scotland (Witcher et al 2000). Research by the Policy Studies Institute and the National Centre of Independent Living (2000) found that consultation with key stakeholders south of the border revealed a clear consensus that direct payments need to be geared towards enabling disabled people to achieve maximum choice and control in their everyday lives. Flexibility, responsiveness, honesty and openness were identified as being vital to making direct payments a success: this is echoed in other UK studies. However, notwithstanding the fact that direct payments have been promoted by the disability movement as a means of empowering disabled people, they have been resisted by some trade unions, local authority social services departments and health and social service trusts, since they can be seen as undermining the power of public sector workers. Research in Scotland (Witcher et al 2000, Pearson 2004) reveals slow progress in implementation, with initial confusion among local authorities about what direct payments are and how they operate. Recipients in 2000 did not include anyone from Black and minority ethnic communities. Following Witcher et al's report, the Scottish Executive funded a voluntary agency, Direct Payments Scotland, to promote take up. In addition, the Community Care and Health (Scotland) Act 2002 made it a duty, rather than a power, of local authorities to offer direct payments. Ongoing research by Riddell et al is looking at variations in policy and practice at national and regional levels in the UK in relation to different groups of disabled people, the different types of state regulation employed and the extent to which local authorities have changed their culture and practice to facilitate access to direct payments for disabled people.

2.154 Another way to use public funds to support disabled people while increasing their choice and control over care arrangements is service brokerage. This involves placing a negotiated sum of money under the control of the service user who is given advice, information and practical help from an independent service broker. However, this model, well developed in Canada, has been little taken up in the UK (Dowson 1995).

2.155 A study about service use and needs among people with motor neurone disease in Scotland (van Teijlingen et al 2001) identifies constraints on users' ability to make choices and feel in control of their support, given delays in the delivery of services and equipment from the statutory sector. The authors highlight the vital role of the voluntary sector in supporting these users. Similarly, another study focusing on one impairment group, this time people with acquired brain injury, reports that users were generally very satisfied with the support received from a voluntary organisation. They had a sense of being at the centre of the service with staff respecting their rights to make decisions. Somewhat in contrast to this, a Scottish study of 'floating' support, while again reporting widespread satisfaction among users, found little evidence of user choice or control, with respondents apparently having little understanding of their entitlements to support nor how it was funded. What mattered more to them, however, was the responsiveness and flexibility of services and the provision of a range of practical, emotional and moral support.

2.156 As indicated already, there is evidence that people from Black and minority ethnic communities do not enjoy much choice and control in social care provision, nor find services flexible and responsive. Service providers may label people from different ethnic groups as non-conformist, because they do not fit neatly into existing provision, and their access to care may be hampered by cultural stereotypes, for example about the role of extended families.

2.157 There is a high level of unmet personal care needs among refugees and asylum seekers, coupled with a lack of knowledge about entitlements and how to get a community care assessment. This is matched by confusion between local authorities and refugee agencies about responsibility for financing community care packages. Vernon (2002) discusses problems achieving user defined outcomes in community care for Asian disabled people.

#### *Research about different impairment groups*

2.158 As mentioned above, policy and practice in the social care field tends to be impairment specific and, as we have already seen, this is often reflected in impairment specific studies. A common theme in many of these studies is gaps in services and shortage of appropriate provision for particular groups. Particular issues have been identified for people with visual impairment, for example, whose mobility and communication difficulties are said to cause problems in accessing services.

#### *People with early onset dementia*

2.159 Research about support to people with early onset dementia reports that the number of people affected in Scotland is not known and that they are a neglected group, with service providers assuming that families will provide care. There is a need for age appropriate services and activities, including day care and short breaks. These access issues, small numbers of potential service users and their geographical dispersal were found to be key to provision - or lack of it - in Beattie et al's (2005) study of services for people with early onset dementia in the South West of England. The care needs of the younger person with dementia are complex. The individual may be physically fit, be in employment and have children: therefore the services available for older people with dementia may not be appropriate (Alzheimer Scotland Action on Dementia 2003). Younger people with dementia have been

found to use community resources less than older people and are more likely to be placed in more costly institutional care (Harvey 1998). Age appropriate services are often stressed as the way to develop good practice with people with early onset dementia, along with a range of appropriate services such as day care, pre and post diagnosis counselling, and ongoing assessment (O'Donovan 1999).

2.160 An evaluation of a service designed to provide high quality social care found that the staff role is crucial. Staff need to be friendly and approachable, respond promptly to need, relate well to the person with dementia, and give reassurance to the individual and their families (Reed et al 2002). Similarly, good relationships with staff were found to be key in a supported living facility (Cantley and Smith 2000) and a home support service (Parsons 1999). However, the latter also reported considerable satisfaction with the service they received as it was reliable, punctual, flexible and provided continuity and consistency of care.

2.161 A holistic model of care underpinned a specialist, age appropriate service, involving joint working, which was found to be beneficial for younger people with dementia (Reed et al 2000). Joint working was also reported as a key to success in the evaluation of the Alzheimer Society of England and Wales project for younger people with dementia (Cantley, Smith and Harris 2002).

2.162 The need for specialist knowledge and training of staff working in this area has been discussed (SNAP 2000, Quinn 1996, Gillan and Gardner 1999), including training for those working with people with alcohol related brain damage (Cox, Anderson and McCabe 2004). Such training would encompass knowledge about the condition as well as the specific care needs of younger people with dementia. However, training is only part of the answer to providing high quality services: the recruitment process must look for people with the right personal qualities to which training can add specialist knowledge.

#### *People with profound multiple impairments (PMI)*

2.163 Research in this field has also identified a need for knowledgeable and specialised input based on evidence based staff training: a significant gap exists between the knowledge base provided by research and the realities of service delivery. In relation to people with PMI, evidence is available about choice, communication, understanding, 'behaviour state' (meaning a continuum of alertness – sleep), challenging behaviour and increasing competence (see Hogg 1998). This knowledge needs to be harnessed in staff training, in planning activities offered to users and in improving management structures in day, residential and leisure settings. Hogg (1999) emphasises that placing people in 'ordinary' settings does not in itself ensure a good quality of life: staff have to take positive and proactive steps to realise the potential benefits. For example, because a person with PMI is generally reliant on others to initiate and maintain communication, service managers must ensure that close attention is paid to 'the quality and quantity of interactions' between service users and staff. Hogg et al (2001) explore how far the entire staff group in one day centre agreed on the expression of emotions by individual service users whom they knew, as well as the influence of context on their judgement. Results showed considerable variation in responses. A study of young people in healthcare settings found that, in one residential unit, staff did not use any communication aids with young people with PMI, claiming they were sufficiently familiar with each person to 'know' what they were feeling (Stalker et al 2003).

## **Good Practice**

2.164 The Prime Minister's Strategy Unit (2005) identifies the following principles of policy design:

- disabled people at the centre
- adequate, timely and coordinated interventions
- meaningful choice for disabled people between services
- a voice for disabled people to influence policy design
- accountability to disabled people.

2.165 Aspects of good practice in direct payments schemes are identified by Witcher et al (2000). Grewal et al (2004) give examples of projects and initiatives which have successfully tackled barriers to service provision at times of transition while Lomas (2000) offers a checklist of good practice in services for people with visual impairment. The Connections service, which supports people with acquired brain injury, is commended by Cunningham et al (1998). Herd and Stalker (1996) outline good practice for planners, purchasers and providers wishing to involve disabled people in aspects of planning, managing and delivering social care services.

## **Gaps in the evidence base**

2.166 The following areas have been identified as needing further research:

- social care services for people from Black and minority ethnic communities, including refugees and asylum seekers
- different models of offering particular activities to adults with PMI
- long term effects of making changes to the environment of people with PMI
- recruitment and selection of staff working with people with PMI
- maintaining morale of staff working with people with PMI.

## SECTION 11: HEALTH CARE – NEEDS AND SERVICES

### Publications profile

2.167 The large number of publications in this section differs, as a whole, from those on other topics. A substantial proportion present exclusively Scottish research or evidence; almost half are either journal papers or refereed conference abstracts and only a few studies have used exclusively qualitative methods. The first feature perhaps reflects the dominance of health related studies within disability research in Scotland while the second and third features may point to a medical orientation within research about health care for disabled people. However, medical research and studies only relating to people with specific chronic medical conditions or illnesses have been excluded.

#### There are 46 publications in this section:

- 18 reports
- 15 journal papers
- 5 refereed conference abstracts
- 2 briefings papers
- 4 web publications
- 1 book
- 1 book chapter

#### *Type of evidence*

- 26 research studies, 11 using quantitative methods, 7 using qualitative methods and 8 using a mix
- 6 literature/ policy reviews
- 7 service reviews
- 3 conference proceedings
- 2 national statistics publications
- 2 development projects

#### Geographic location

- 32 Scotland
- 12 UK
- 1 England
- 1 International

*Disabled people's perspectives included in 25 studies*

### Summary of main findings

#### *Statistics*

2.168 The majority of younger disabled people describe their health as 'not good' (Social Focus on Disability, Scottish Executive 2004b, Chart 6.1). The SHS collects information about types of ill health and impairment and also about types of activity which the person finds difficult to manage. Social Focus on Disability does not provide age breakdowns of the results.

## *Overview*

2.169 We have found no recent overview of health care provision for disabled people in Scotland: the most recent work identified is the study, mentioned in the previous section, of social work and health services to disabled people commissioned by the Scottish Office in 1994 (Stalker and Reddish 1996). In their baseline study for the Disability Rights Commission in Scotland, Riddell and Banks (2001) do not identify any other health care research. Key findings in 1996 included the ‘Cinderella’ nature of health services for disabled people, with acute services receiving the bulk of resources (although it was suggested their role in treating disabled people was likely to diminish due to growing pressure to increase through-put and develop alternatives to hospital admission). Rehabilitation services were unevenly developed across Scotland and, in some areas, fragmented and inadequate. A need was identified for more Specialist Nurse Practitioners to provide ‘middle range’ medical advice and counselling to people with chronic or degenerative conditions. There was a shortage of physiotherapists, speech therapists and/ or incontinence services in some areas. User involvement in health services was generally underdeveloped. It is worth noting that the Prime Ministers’ Strategy Unit (2005) describes the response to disabled people’s health needs as generally piecemeal.

2.170 The medical world’s perceived capacity to control the environment in which disabled people live is discussed by Begum (1996). Noting the concern among disabled people about the pervasiveness of the medical model of disability within healthcare services, she argues that the medical profession should support people in managing their impairments and illnesses in ways which the latter define as helpful and appropriate. The social model is not irrelevant to GPs for example, Begum argues, since it provides a framework for recognising both individual impairment and social barriers. Participants at a conference organised by the Scottish Executive (2001) to review disability research questioned the definition of ‘disabled person’ used by the DDA on the grounds that it reflects a medical model of disability. They also called for more qualitative and holistic research on health care.

## *Access to services*

2.171 A study by the Scottish Consumer Council (2001) exploring access to primary care services collected evidence through focus groups with, among others, disabled people and their carers. Its report gives recommendations on improving access to primary care trusts and Local Health Care Cooperatives. Scottish Human Services Trust (2003) reports proceedings from a conference it convened to discuss ways of improving disabled people’s access to healthcare provision. It notes that efforts to improve access should not be confined to the built environment but must extend to developing inclusive attitudes and practices, if individuals’ diverse needs are to be recognised.

2.172 The Disability Rights Commission/ Scottish Executive Health Department/ NHS Scotland (in progress) are conducting a research and development project entitled Fair For All, aimed at improving disabled people’s access to and experiences of health care in Scotland. The initiative includes a baseline survey of health boards to assess current awareness and understanding of disability equality and the provision of reasonable adjustments for disabled people throughout the NHS in Scotland, the establishment of a support network for disability advisors and the production of health specific guidance in



meeting the needs of disabled customers. Results will be published in a DRC Baseline Study in Spring 2005.

### *Rehabilitation and quality of life*

2.173 A number of studies explore aspects of rehabilitation services in relation to quality of life for disabled people. On the positive side, Boa and MacFadyen (2003) report the value of involving people with communication impairments in setting their own goals for rehabilitation; Chesson et al (1999) discuss the benefits, reported by staff and patients, of a writer-in-residence post within a rehabilitation unit. More worrying findings are reported by Laurie and McMillan (2004) who, as already mentioned in this report, identified 92 'young' adults with a wide range of physical impairments living in nursing homes in Glasgow. Most homes were staffed by unqualified assistants, supervised by nurses. None offered rehabilitation and proactive medical review was uncommon. Low levels of satisfaction with health, social and voluntary services among amputees is reported by Whyte and Carroll (2002) although McCartney et al (1999) stress the importance of pain relief and rehabilitation in improving quality of life for people who have undergone lower limb amputation. While grateful for the initial life saving care provided to 20 young people with head injury, their parents were dissatisfied with the subsequent level of care in general wards (Hubert 1995). Supporting services were often withdrawn too early, with families wanting more advice, support and specialist counselling.

### *Collaboration and joint working*

2.174 The importance of collaboration among health professionals, and between health professionals and colleagues from other disciplines, is a recurring theme. The role of health professionals within care management is highlighted by Stalker and Campbell who report that, in 2002, Scottish NHS Trusts employed 115 care managers. Joint working was widely seen as key to good practice but was unevenly developed across Scotland. Occupational therapists were well represented among care managers. The need for OTs to develop closer joint working across primary, community and secondary health services is highlighted elsewhere, along with a need to make OT services available in more community settings as opposed to hospital based practices. Collaboration between professionals within stroke services is discussed by Bisset et al (1997), and among health services treating people with early onset dementia, where joint working between neurologists and old age psychiatrists is described, in a UK wide study, as less than ideal (Corney et al 2002). Other research stresses the importance of good collaboration between children's and adult health services, if young people are to experience a smooth transition. SCIE (2004) notes that some youngsters experience a deterioration in their health following the move to adult provision, and report a concern among paediatric staff that, in relation to some diseases, treatment expertise in adult services is at a low level. This review notes that most research on transition has focused on young people with chronic conditions rather than physical impairment and that individual studies tend to be confined to specific conditions.

### *People with multiple and profound impairment (PMI)*

2.175 As well as a high level of cognitive impairment, people with multiple and profound impairment

“will have other physical disabilities and sensory impairment or both. Most will also have significant healthcare needs. 66% will have severe epilepsy, most will have difficulties in eating and drinking and problems with their breathing” (Scottish Executive, 2004: 92).

2.176 Hogg (1999) reviews research about understanding and realising the needs of people with PMI across the UK. He notes that significant challenges exist in meeting their personal, developmental and healthcare needs. It is suggested that people’s ‘often extreme’ needs for healthcare are being better met following advances in medicine and increasing awareness that, for this group, good healthcare is critical to overall quality of life. Individuals’ healthcare needs can be pervasive, requiring input from mainstream community medical services and specialist providers. Hogg warns that, in the current trend to favour mainstreaming, the value of specialist expertise should not be forgotten. There is a paucity of research on mental health in this area although recently there has been greater awareness of the affective and emotional needs of people with PMI. Phillips et al (in progress) are conducting a study exploring how family and professional carers identify changes in the mental well-being of young people with PMI and the ways they respond to such difficulties. Whinnet (in progress) discusses the benefits of involving parents in training health care staff in the special needs of their sons and daughters, resulting in considerable benefits for all concerned.

2.177 The costs of services to people with PMI vary greatly but are generally dearer than provision for more able people with learning disabilities, due to the higher need for specialist therapeutic and nursing support. If cost utility is not optimised, there is a risk that investment may not be seen as worthwhile, resulting in reduced resources and lower standards (Hogg 1999).

### *People with early onset dementia*

2.178 Prevalence of dementia has been the concern of some literature, one study estimating that 1 in 1000 people under 65 will have early onset dementia (NHS Scotland 2003) and Alzheimer Scotland estimates that there are around 1600 younger people with dementia in Scotland (Scottish Executive 2004e, 1). There is a problem in the usage of the term ‘early onset dementia’; during this scoping study it was found that ‘early onset dementia’ was often used synonymously with ‘early stage dementia’. Thus, discussions about ‘early stage’ dementia may or may not include people who are younger who have early onset dementia. A further difficulty is that discussions about ‘early onset dementia’ may also refer to younger people with dementia (under 65’s) who have another form of dementia, such as acquired brain damage or Huntington’s disease (e.g. NHS Scotland 2003, SNAP 2000, Cox and Keady 1999, Woodburn and Johnston 1999a). The SNAP report (2000) provides an overview of the state of service provision for younger people with dementia, specifically, early onset dementia, Huntington’s Disease and acquired brain injury. In addition, individuals may have

multiple and complex service needs that are met in a variety of ways, for example people with alcohol related disease may receive services designed for one or more of the following groups – people with dementia, older people, or those with acquired brain injury (Cox, Anderson and McCabe 2004).

2.179 Information services provide an important resource for service users, families and health professionals throughout the progress of the dementia, helping inform them about the availability and appropriateness of different forms of treatment and service provision (Harvey et al 1998). However, the frequency of use by those with, or caring for, someone with early onset dementia is not specified.

2.180 A nationwide survey of mental health services (NHS Health Advisory Service 1996) revealed inconsistency in services on offer, suggesting there may be lack of staff knowledge, inappropriate services and a lack of specialist advice. This reflects the general debate within early onset dementia services, about whether services should be specialist or generic.

### **Good practice**

2.181 Stalker (2002) reports a project run by Forth Valley Primary Care NHS Trust called ‘Smoothing the Transition’ which aims to facilitate young people’s move into adult health services. She also cites a resource pack entitled ‘Walk the Talk’ (Scottish Executive 2000) aimed at improving primary health services for young people. The pack cites a good practice project in Scotstoun, Glasgow, led by Westone LHCC District Nursing Team, which aims to help young disabled people maintain their independence.

2.182 A project by Miller (in progress) is developing local and national networks to disseminate, generate and share good practice among Allied Health Professionals in relation to better standards of healthcare for people with PMI. The Scottish Executive (2000) identifies the Epilepsy Association of Scotland as an example of good practice in providing guidelines for training staff in inserting rectal diazepam.

### **Gaps in the evidence base**

2.183 Specific topics identified as needing further investigation include:

- holistic and qualitative studies incorporating users’ perspectives
- the health care needs of disabled people from Black and minority ethnic communities
- the mental health needs of people with PMI; raising awareness of these among families and professionals; how best to respond to and treat mental distress in this population
- more development of methods for evaluating health care interventions for people with PMI
- experiences of amputees in gaining and sustaining employment; employers’ perceptions
- reasons for low level of use of health and social work services by amputees.

## SECTION 12: EQUIPMENT AND ADAPTATIONS

### Publications profile

2.184 Only 9 research studies have been identified relating to equipment and adaptations: other publications included here take the form of service/ policy reviews, conference proceedings, consultation responses and national statistics. On the plus side, however, most of this work relates directly to Scotland. We have not included studies and reports emanating from individual local authorities which focus on detailed accounts of local provision.

#### There are 17 publications in this section:

- 14 reports
- 3 journal papers

#### *Type of evidence*

- 9 research studies, 5 using qualitative methods, 1 using quantitative and 3 using mixed methods
- 3 service reviews
- 1 policy review
- 2 national statistics publication
- 1 conference proceedings
- 1 set consultation responses

#### *Geographic location*

- 13 Scotland
- 2 UK
- 2 England/  
Wales

*Disabled people's  
views given in 11  
publications*

### Main findings

#### *Statistics*

2.185 Social Focus on Disability publishes an age breakdown from the SHS of people with an impairment who have, or need, special equipment or adaptations (Scottish Executive 2004b pp 85-87). The figures show that for this group, 30% of the 35-44 age group and 35% of the 45-59 age group have special equipment or adaptations. For people with both impairment and long-term illness the corresponding figures are 48% and 44%. Results are also available by age group on the proportion of disabled people who need special equipment or adaptations which they do not currently have. For people with an impairment, 17% aged 35-44 and 20% aged 45-59 needed equipment or adaptations. For people with both impairment and long-term illness the corresponding figures are 31% and 25%. Other results relating to the type of equipment are not broken down by age.

2.186 The Scottish Household Condition Survey 2002 (Communities Scotland 2003) reports that about 1 in 10 households include someone using a mobility aid. The majority of

households requiring an adaptation require only one change, most commonly handrails, followed by adaptations to a bath or shower.

### *Overview*

2.187 An overview of the law underpinning the provision of equipment and adaptations in Scotland is given by Mandelstam (2003). Starting with an introduction explaining the importance of policies in this area being informed by law, he goes on to summarise the relevant legislation and legal principles, illustrated by practical examples.

### *Delays in provision*

2.188 A recurring theme in the publications on this topic is long waiting lists and delays in providing a service. The earliest report included (Stalker et al 1995), which provided an overview of the roles and tasks of occupational therapists, noted that information about waiting list numbers was poor because data were not recorded systematically nor consistently across Scotland. Nevertheless, the authors estimated that between 15,000 and 16,000 people were waiting for assessments and around 10,000 for the provision of aids and equipment, with considerable variation between different parts of the country. The report of a Scottish OT conference held five years later again highlighted waiting times for service provision, and slow decision-making processes, echoed in a study by Hall (2001). This research reported that waiting times were 'far greater' for adaptations than for equipment, identifying authorisation of funding and lack of delegated decision-making as the main sticking points. Van Teijlingen et al (2004) conclude that voluntary organisations are having to fill the gaps in provision available from the statutory sector but, in doing so, may be masking the real extent of the problem. They report that service provision is better in the east than the west of Scotland.

### *Developing ideas and approaches*

2.189 Within the various publications about equipment and adaptations issued in Scotland over the last decade, it is possible to trace significant changes in policy and practice. These appear to be informed by changing views about the underlying purpose of providing equipment and adaptations to disabled people, and how that service fits into wider developments within this field. Thus in 1995, most occupational therapists spent the majority of their time (77%) assessing for and providing equipment and adaptations. By the turn of the century, there were more calls for some change of emphasis or direction, in order to provide joined-up person centred services. It was argued that existing structures and arrangements should not remain static, but that occupational therapy could not achieve the necessary changes alone. OTs were said to be hampered in completing rehabilitation work with disabled people by various organisational and resource related constraints. Users and professionals lacked information about the skills and services OTs could offer. Key changes needed were better joint working, more user involvement, with a review of current approaches to customer care, and a refocusing of the service away from hospital settings and into the community. By 2003, the language had shifted again to noting environmental barriers which affect disabled people's ability to participate in mainstream employment, educational, and social opportunities. The 'strategic vision for equipment and adaptations' is now said to

go beyond service provision to address equality and social justice issues for older, disabled and ill people. Similarly, Dewsbury et al (2004) describe domestic design issues as moving away from a 'special needs' approach to a more universal and inclusive form, while Heywood (2004) emphasises that adaptations must not be carried out in a 'disempowering' manner.

## **Good practice**

2.190 Most publications make recommendations for further improvements in the provision of equipment and adaptations, from which the following features of good practice can be inferred:

- speedy decision making process about provision and funding
- mainstreaming of provision, with easy access through commercial outlets
- inclusive design of products, housing and the environment through harnessing the potential of emerging technologies
- accessible information, supported by advice and demonstrations
- accessible and positive presentation of information within the adaptations literature
- well integrated equipment and adaptations, within the context of care management and single shared assessment, across user groups and through joint resourcing and management
- well kept and regularly updated records of adapted property.

## SECTION 13: TECHNOLOGY AND COMMUNICATION

### Publications profile

2.191 There are no national statistics on technology and disability. However, this section includes a relatively strong portfolio of research conducted in Scotland by Joan Murphy and colleagues in the area of technology for assisted communication. The burgeoning area of research in relation to technology and the home (Dewsbury et al 2004, Gann et al 1999) was discussed in Section 7 on housing.

#### **This section is based on 15 publications:**

- 4 reports
- 10 journal papers
- 1 weekly bulletin

#### ***Type of evidence:***

- 2 policy/ literature reviews
- 10 research studies, 1 using quantitative methods, 6 using qualitative methods, 3 using a mix of qualitative and quantitative methods
- 3 service reviews

#### ***Location of research***

- 8 in Scotland
- 3 in the UK
- 2 England
- 2 international

*Disabled people's perspectives included in 8 publications*

### Summary of main findings

#### *Information provision*

2.192 Harvey et al's (1998) evaluation of CANDID – a national telemedicine service supporting the care of younger people with dementia, their families and professionals - found that respondents called for general information, clinical advice, and advice on social issues. It also found that families and the public used the service more than health professionals did.

#### *Facilitating communication*

2.193 Only 12 % of disabled people in Scotland have personal access to the Internet compared to 39% of the non-disabled population (2001/02 Scottish Household Survey,

quoted in DRC 2005). Research by Seymour and Lupton (2004) conducted in Australia intimated that the 'real promise of cyberspace' for disabled people lies in its potential to escape the 'able-bodied – non able-bodied' distinction, rather than 'bodily escape' per se. They note that text is a common language through which to communicate online in a place where access is not determined by physical ability. They found however that 'disability identities' might effectively deter some disabled people from exploring potentially beneficial new technologies. Research carried out in England (Pilling et al 2004) found that almost all respondents welcomed the Government's initiative to put information about services on line, with the proviso that alternative communication methods remained available. Those who were unable to leave their homes, those who found writing or reading common forms of print inaccessible and those with speech impairments, stated that Internet usage enabled them to communicate with others and to reach a variety of information sources. Two thirds of respondents intimated that they would use the Internet more if they were not constrained by issues of cost. Similarly, the study found that the financial costs associated with buying a computer, of arranging on-line access and of assistive devices were the most common reason preventing non-users from getting on-line.

2.194 Boa and McFadyen (2003) found that Talking Mats, a 'low tech' form of communication using picture symbols, aided both people with very mild communication impairments as well as those with severe difficulties to set goals for their rehabilitation. The study also found that, whilst some patients had different priorities to those of the rehabilitation staff working with them, Talking Mats helped people focus on and talk about specific areas of their lives.

2.195 Murphy et al (1995) note that, in 1991, 72 children, 37 adolescents and 107 adults with cerebral palsy in Scotland were using some form of Augmentative and Alternative Communication (AAC) system in both formal and informal settings. In addition to AAC, this study also found that users employed their own idiosyncratic forms of non-verbal communication, as well as other, more formalised, symbolic systems. Research in Scotland (McCall et al 1997), exploring users' and communication partners' perspectives of AAC systems, found that both high and low technology systems were seen as having advantages and drawbacks in three areas: the effect of the AAC on users' communication, features of the AAC system and the effect of the AAC on users' quality of life. This study also demonstrates the important contribution to be made by AAC users in developing new priorities based on their own experiences.

2.196 In comparing the attitudes and activities of speech and language therapists (SLT) and non speech and language therapists in direct work with adults who use AAC in Scotland, Murphy (1997) found that, whilst speech and language therapists have wide ranging skills in the area of communication, many were not comfortable with technological aspects like positioning, access, mounting, and repair of equipment.

2.197 The most recent research by Murphy (2004) into the perceptions of AAC held by people with motor neurone disease, raises theoretical and practical issues for professionals who work with and provide services to families. The author notes that AAC was apparently less successful than had been anticipated for this group because of 'their need for social closeness' - which might not be possible when using a device - and the complexity of learning how to use a high technology device, combined with adequate training.



### *Other research*

2.198 In a preliminary study designed to measure the effects of seating on people with profound intellectual and multiple disabilities, Neilson et al (2001) found that patients benefited both physically and functionally as a result of customised moulded seating. Benefits were apparent in terms of quality of life, sitting posture, eating and carer satisfaction.

2.199 More adequate training (in aspects of technology) is required to provide for the very specific needs of people with PMI (Scottish Executive 2000). An international review of research about *Snoezelen*, multi-sensory environments created for educational, therapeutic and leisure activities with people with profound intellectual impairments, noted that some studies report that using *Snoezelen* helps improve the quality of social-emotional interactions between staff and service users, although they also identify a need for more research in this area (Hogg, Cavet, Lambe and Smeddle 2001).

### **Good practice**

2.200 The following pointers to good practice are reported by Joan Murphy and colleagues:

- encouraging and supporting speech strategies for as long as possible, particularly when disabled people wish to use their own speech
- being aware of the range of service users' communication purposes, including the wish to share thoughts, engage in small talk and maintain social closeness, which may not always be helped by high tech communication devices
- providing service users with information about vocabulary choices when introducing an AAC device, including how to express emotion and explain how they want things done
- using low tech systems like Talking Mats where appropriate.

### **Gaps in the evidence base**

2.201 The following gaps in the evidence base were identified:

- more research is needed to establish why 22.2% of the AAC users in Murphy et al's (1995) study employed their AAC systems only in formal (i.e. therapy and educational) contexts
- Murphy (1997) suggests the following areas for further consideration: areas of AAC work which should be solely the province of speech and language therapists; areas that could be better carried out by non speech and language therapists; identification of tasks that could be carried out collaboratively and how training should be provided
- a review of existing information standards – emphasising alternative communication mediums, including the availability and usefulness of information technology - was welcomed in a recent Action Plan for community care services for people with a sensory impairment (Scottish Executive 2004a)
- exploring the impact of *Snoezelen* on the quality of social-emotional interactions between staff and service users has been suggested (Hogg, Cavet, Lambe and Smeddle 2001).

## SECTION 14: FAMILIES AND CARERS

### Publications profile

2.202 The title of this section reflects the fact that disabled people's relatives do not necessarily act as their 'carers', nor are people's carers necessarily their relatives. There is a vast literature on caring and carers in the UK: the main focus here is on studies about relatives/ carers of disabled people in Scotland. The majority of this research is small scale, qualitative and impairment group related, reflecting much of the wider carers' literature.

#### There are 32 publications in this section:

- 11 reports
- 12 journal papers
- 3 conference abstracts
- 2 briefings papers
- 1 research proposal
- 1 book chapter
- 2 web publication

#### *Type of evidence*

- 18 studies, 10 using qualitative methods, 3 using quantitative methods and 5 using a mix
- 7 policy/literature reviews
- 2 sets national statistics
- 5 service reviews

#### *Geographic location*

19 Scotland  
11 UK  
1 England  
1 International

*Carers' perspectives  
given in 12 studies,  
disabled people's in 8*

### Summary of main findings

#### *Statistics*

2.203 In the 1996/7 Disability Survey, only 15% of all disabled people used social services. Self-perceived need for support was much higher with 40% needing help with practical tasks, 19% with personal care in the day and 13% at night. These proportions were similar for all adult age groups. Nearly two fifths of people needing regular care received support from their partner for at least one task and a similar proportion relied on other informal help within the household. The 5% of people with the most 'severe' impairments were more likely than others to receive formal help (32% compared with 21% of all disabled people).

### *Range of relationships*

2.204 Several studies remind us that disabled people's relatives are not necessarily their carers, or have exclusively 'caring' attitudes towards them. For example, it should not be assumed that children and young people will take on caring responsibilities for their disabled parents, or for other members of their household (Banks et al 2001). Only a minority do so and usually as secondary rather than primary carers. In a small scale study in one Social Inclusion Partnership area in Scotland, Banks, Cogan, Riddell, Deeley, Hill and Tisdall (2002) report that just over 6% of pupils who completed a questionnaire helped look after a family member with an impairment or illness. Several children had told no-one about their family circumstances.

2.205 Similarly, it is often assumed that people with early onset dementia will be cared for by their families (Tindall and Manthorpe 1997, Beattie et al 2002). The impact of diagnosis on the children of people with this condition has been considered by Robertson (1996). The young people usually told their friends about the diagnosis but rarely invited them home. Their responses to this diagnosis included feelings of hopelessness, shame, embarrassment and irritation and a negative impact on relationships between parents and offspring was reported.

2.206 Young disabled people's experiences of abuse and violence at the hands of their partners are described by Hendey and Pascall (1998) who identify this as a neglected policy area.

### *Timing of support*

2.207 A few studies refer to critical points at which carers require support, for example, in relation to people with early onset dementia, at the time of diagnosis, since the emotional impact on families at that time can be severe (Alzheimer Scotland Action on Dementia 2003) and when the person's condition deteriorates (Robertson 1996); in relation to carers of people who have had a stroke, initially and in the early stages of recovery (Smith, Lawrence, Kerr, Langhorne and Lees, 2004). Carers of people with early onset dementias also need support following bereavement (O'Donovan 1999). Parents' and carers' roles change as young disabled people move into adulthood, even if they are still providing a good deal of care: professionals should involve and support parents in transition planning and be sensitive to their feelings. Of course these findings do not imply that carers can be left to get on without any support the rest of the time!

### *Stress, needs and services*

2.208 The carers literature has been criticised for its emphasis on the 'burden' of care and its neglect of users' (as opposed to carers') perceptions (Bytheway and Johnson 1998). Overall, the studies scoped in this section do not frame caring as a burden, suggesting that some researchers have moved on in their thinking. (However, only eight studies canvassed disabled people's views). The stresses and strains that can be entailed in looking after a family relative on a long term basis are acknowledged but overall the focus is on identifying carers' needs and evaluating the services available. A study by Hirst (2004) – commissioned by a carers' organisation - is one exception, comparing health problems among carers with

those of the general population. His findings highlight the physical, psychological, social and financial stress faced by some carers and the isolation many experience. Harvey (1998) also reports high levels of 'stress and burden' among carers of younger people with dementia, while a CHSR (1999) study found that carers of younger people with dementia perceived a decrease in their standard of living since caring. Even when short breaks are provided for the carer they may use this to catch up on household chores rather than for the social or recreational purposes which the service is intended to promote (Paraho, Campbell and Scotlock 2002).

2.209 Needs identified among carers are often presented as specific to those looking after people with particular impairments but some recurring themes can be identified. There is a widespread need for better and more accessible information, for fuller assessments of carers' needs, for regular person-centred short breaks, for day time provision to complement family care-giving, counselling and support groups. Recommendations have been made for services to support carers of people with early onset dementia, including information services and advocacy for carers (SNAP 2000, Quinn 1996, CHSR 1999). One paper reporting on an information service available to families, service users and health professionals suggests a high uptake (Harvey et al 1998). However no specific reference is made to the usage or information given to or about younger people with dementia. There is evidence of the need for - and benefits of - service providers working in partnership with carers, for example, carers' views and expertise being incorporated in assessments of the disabled person, and, conversely, the need for staff to share useful information with families, for example, about the role of new technologies in facilitating care. The interaction of family support, state support and the nature of the disabled person's impairment are significant in determining outcomes (Riddell 1998b).

2.210 A smaller part of the research addresses the services on offer to meet need. Van Teijlingen et al (2001) found that carers of people with motor neurone disease had to rely on voluntary organisations to provide help which was hard to obtain from the statutory health and social work sector, particularly in relation to provision of equipment. A consultation exercise with carers in Stirling makes recommendations about transport, personal support for carers and joint working.

2.211 There have been a limited number of studies about 'young carers' in Scotland, which should be seen as part of a wider – and contested - literature on this topic, most of which has been conducted in England (see Keith and Morris 1995, Aldridge and Becker 1996 and Olsen and Parker 1997 for this debate). Some families are wary of involvement with services for fear of intrusion into their homes and privacy or, at worst, removal of their children (Banks, Cogan, Riddell, Deeley, Hill and Tisdall 2002). These authors conclude that disabled adults should receive sufficient support to prevent children and young people having to act as carers in the first place. However, where they 'choose' to do so, 'young carers' are said to need support and guidance, befriending and advocacy, with greater exploration of innovative forms of service delivery. While considerable data are available about 'young carers' support projects - with largely positive findings reported - there are also significant gaps in knowledge about statutory provision, assessment processes and the impact of different approaches to delivering services for 'young carers'.

## *Research methods*

2.212 Two publications deal with research methods. Arksey et al (2004) give guidance to those wishing to evaluate the evidence about support services for carers. They suggest that defining the meaning of ‘effectiveness’ when assessing carers’ support services presents a significant methodological challenge and that available measures are unsatisfactory. They point out that a high standard of good quality effectiveness data is needed for economic evaluations and that few such studies have been published. Addressing a more specific issue, Neilson et al (2000) discuss effectiveness measures in relation to healthcare interventions for people with PMI and their carers, although they too discuss cost effectiveness and quality of life issues.

## **Good practice**

2.213 Whinnett (2004) describes a development project in which mothers of young people with PMI were involved in training staff delivering health care packages to their sons/daughters. Reported benefits to families included

- better support during periods of ill health
- unbroken sleep
- prevention of burn-out
- improved family life
- development of trust in paid carers.

2.214 Skills and knowledge acquired by paid carers included

- awareness of a young person’s communication needs and ability to meet them
- understanding of the principles of home care for young people with specific medical needs
- ability to understand, explain and competently demonstrate procedures such as gastrostomy and airway suctioning
- understanding of, and ability to administer, medication as appropriate.

## **Gaps in the evidence base**

2.215 There has been a huge amount of research about carers across the UK so this is unlikely to be a priority area for further work. However, research on carers’ experiences of assessments following the implementation of the Community Care and Health (Scotland) Act 2002 would be useful.

## SECTION 15: UNMET NEED

### Publications profile

2.216 Although a large number of publications are included in this section, most of them are not studies of unmet need as such. However the fact that so many disability studies include findings about unmet need is suggestive. The majority of these publications are reports or journal papers and nearly half of them relate specifically to Scotland. Users' perspectives are included in half of this work. It is interesting and may be of concern that no national statistics are kept about unmet need.

#### **There are 45 publications in this section:**

- 20 reports
- 16 journal papers
- 2 conference abstracts
- 1 web publication
- 2 book
- 1 book chapter
- 1 briefings paper
- 1 not known
- 1 unpublished paper

#### ***Type of evidence***

- 28 studies, 10 using qualitative methods, 11 using mixed methods, 6 using quantitative methods and one pilot study
- 9 policy/literature reviews
- 7 service reviews
- 1 set consultation responses

#### ***Geographic location***

- 22 Scotland
- 17 UK
- 5 England/ Wales
- 1 other

*Disabled people's views included in 23 publications*

### Findings

2.217 There are a number of ways in which unmet need is approached in the literature and thus, various ways in which the findings can be presented - in terms of structural/ attitudinal barriers, impairment groups, type of unmet need, shortage of particular services and/or the perceived shortcomings of particular services or service providers. Much of the material in this section has already been covered elsewhere so, to avoid repetition, will not be discussed in detail here.

### *Structural/ attitudinal barriers*

2.218 Several studies approach the question of unmet need in terms of structural and/or attitudinal barriers which discriminate against disabled people. Thus, Henderson and Henderson (1999) describe inaccessible transport provision; McKenzie (2002) discusses barriers in accessible housing while barriers in higher education are investigated by several authors. Barriers within retail and /or leisure facilities are discussed in a few studies, MacDonald (1996) for example pointing to the built environment and the lay out and presentation of goods within shops as hampering access to services. Low income is another factor which affects unmet needs for disabled people: costs of living are explored by Smith, Middleton, Ashton-Brooks, Cox, Dobson with Reith (2004), who note that disabled people face additional costs in most areas of everyday life. As already seen, the unmet needs of Black and minority ethnic communities are discussed in a number of studies, with accessible information about entitlements and services, and cultural sensitivity and flexibility within services being key themes.

2.219 Alongside the physical and economic barriers which cause or contribute to unmet need, there is ample evidence of attitudinal barriers having a similar effect. For example, a need for better understanding and awareness of disability issues has been identified among transport workers, retail and leisure centre staff, and service providers who hold stereotypical views about various minority groups.

### *Impairment group*

2.220 Evidence is also available about types of unmet need, or the service thought to be required to meet a specific need. Cox and McLennan's 1994 review highlighted the unmet needs of people with early onset dementia. They also highlighted the lack of information about the number of people with early onset dementia and the resultant impact this has on service provision. Both issues have since been reiterated. For example, Cordney et al (2002) highlight the under-investigation of younger people with dementia and the inadequacy of follow up services and Woodburn and Johnstone (1999a) highlight the difficulties in the inclusion of types of dementia which younger people experience.

2.221 It has been suggested that the key way to address unmet need is a collaborative, inter-professional and multi-disciplinary approach for all services offered to younger people with dementia (Cox and Keady 1999). In addition, consulting with service users about their views of services and their care needs may help inform the development of appropriate services (Alzheimer Scotland Action on Dementia 2003, Beattie, Daker-White and Gilliard 2004).

2.222 People with PMI face disadvantage in many areas and are at risk of poor outcomes compared to their more able peers, for example, in relation to choice, social inclusion, employment, active lifestyles and access to leisure and community facilities. There is a need for more proactive support for this group, greater development of individualised residential and daytime opportunities and attention to their mental well-being. Families of people with profound and multiple impairment require better support and information since information about people with learning disabilities often omits people with PMI.

2.223 A range of unmet needs is identified among people with sensory impairments, including information, communication support, rehabilitation support (attributed to a shortage of rehabilitation officers) and advocacy, while basic data about the numbers and needs of deaf-blind people across Scotland is missing. Young people who have experienced head injury have unmet emotional, social and employment needs: their families felt they would have benefited from more advice and specialist counselling.

*Type of unmet need/ missing service*

2.224 Inclusive leisure opportunities and the support required to pursue them are unmet needs among many young disabled people. It is reported that needs for clinical psychology among people with physical impairment are either inadequately, or not at all, met. Neuropsychological and psychosexual difficulties are identified as priority areas. On a different note, the legal needs of disabled people are reportedly unmet, with individuals experiencing difficulty accessing information, advice and assistance about their rights. A range of barriers to obtaining legal services is identified, partly relating to the nature of the legal aid system and partly to the 'pattern of expertise' on offer from lawyers and other agencies. Delays in providing services prolong and may exacerbate unmet needs: this is a particular problem in the provision of adaptations and equipment.

**Good practice**

2.225 Grewal et al (2004) offer various examples of national and local initiatives designed to overcome barriers in policies and services which contribute to unmet need, such as;

- the Connexions Service (in England and Wales), aiming to smooth transitions from childhood to adult activities including further/higher education and employment
- integrating Community Equipment Services, by pooling health and social services equipment stock and budgets
- Access to Work, which gives advice and practical support to enable a disabled person to move into, or remain in, work
- unified teams comprising occupational therapists and housing officials to address difficulties and delays in housing adaptations
- joint assessment procedures
- multi-disciplinary teams
- flexibility in use of health and social care budgets.

2.226 Proposals for further developments include

- raising awareness of services on offer so that professionals can make appropriate referrals
- increased use of key working
- a focus on evidence based initiatives and policies.



## **PART 3: CONCLUSIONS**

### **INTRODUCTION**

3.1 This part of the report presents the study's main conclusions in the light of its aims and objectives. Key themes and issues are identified across the various topics, and placed in the wider context of current theoretical, policy and practice debates. (We were not asked to address policy and practice implications).

3.2 Part 3 begins with a summary of the volume and focus of all the evidence scoped, followed by a commentary on the statistical evidence available. The thematic overview first identifies key emerging issues overall, next, those specific to disabled people's perspectives and roles in decision-making and then those relating to specific groups. Finally, evidence about good practice and gaps in the current evidence base are discussed.

### **SUMMARY OF VOLUME AND FOCUS OF EVIDENCE SCOPED**

3.3 The total number of items scoped in this study was 223, the majority being research studies. Thirty-nine were classified either as research/ policy reviews or service reviews, while 14 were national statistics publications. The majority of the evidence was gathered in, or applied to, the statutory sector although half of these publications also applied to all sectors. Surprisingly few items related only to the voluntary sector and, overall, there was very little information about privately run provision. In terms of geographic coverage, just over half the total number related exclusively to Scotland.

### **NATIONAL STATISTICS AND SURVEYS**

#### **Sources**

3.4 The main sources of statistical information are the Census, national surveys and administrative statistics about service use collected by Government Departments. Social Focus on Disability 2004 is a Scottish Executive publication which brings together statistics from all of these sources. Most of the results are derived from the Scottish Household Survey (SHS), with additional material from the UK Labour Force Survey (LFS), Census 2001 and administrative statistics collected mainly by the Scottish Executive. A further source of statistical information is the 1996/7 Disability Survey for Great Britain produced by the DSS. This followed the 1985 survey and the report of the later survey identifies changes observed between the two. It is not known whether a further survey will be run 10 years on.

3.5 Unlike the Census, neither the SHS nor the FRS includes people who live in institutions or communal establishments such as care homes. Community care statistics are published annually by the Scottish Executive – the most recently published statistics relate to 2004<sup>2</sup> and are available from the Scottish Executive website at [www.scotland.gov.uk/statistics/commcare](http://www.scotland.gov.uk/statistics/commcare). Audit Scotland also provides valuable

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<sup>2</sup> The most recent statistics were published after the majority of this report had been prepared.

information on service provision across Scotland in the form of survey reports and performance indicators (see <http://www.audit-scotland.gov.uk/>). Of marginal relevance to this report is an Audit Scotland performance indicator relating to the qualifications of staff in residential homes for ‘other adults’ i.e. those aged under 65. Some of these data on short term care were reported in Section 10.

## Collection and presentation of statistics

3.7 The way in which information about disabled people is collected and presented depends on the particular purposes of the survey concerned. Differences in the definitions used are discussed in Social Focus on Disability. The Census question asks about ‘limiting long term illness’ which encompasses ‘disability’ both ‘mental’ and ‘physical’ as well as other health issues:

Census 2001 question

Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do? [include problems which are due to old age]

3.8 Census results relating to limiting long term illness are available on the interactive website (SCROL) for all Council areas by general health, economic activity and a range of demographic variables.

3.9 The LFS focuses on disabled people of working age and tends not to distinguish between people who are disabled and people who have a long-term illness, the point of interest being the person’s capacity as part of the workforce. The SHS on the other hand is concerned with households and individuals as citizens and as users of services and collects information about type of impairment, need for care and use of a wide range of services for all age groups.

3.10 In the SHS, a disability is ‘a physical or mental impairment which has a substantial and long-term adverse effect on a person’s ability to carry out normal day to day activities’. This definition is also used in the Disability Discrimination Act 1995. The SHS first asks whether there is anyone in the household with ‘any long-standing illness, health problem or disability that limits daily activity or the kind of work the person can do’. The SHS then goes on to ask the respondent to choose from a list of conditions the ones which best describe the ‘ill health or disability’ that each household member has (Scottish Executive 2004 b, Table 6.6). There is no age breakdown published of the responses to this question.

3.11 Published SHS tables distinguish between disabled people and people with a long-term illness, but not generally between people with physical and mental impairments. There may be scope for analysis of the SHS in the future which focuses on people with physical impairment only.

3.12 Information on severity of impairment is also helpful in an analysis of the needs of disabled people and how they are met. In the SHS, this is restricted to simple yes/no responses to questions about ability to perform everyday activities unaided. The 1996/7

Disability Survey covers a sample of over 7,000 disabled adults in Great Britain<sup>3</sup>. Nearly 10 years on, this survey remains the only published source of detailed statistical information relating to severity of impairment. The questions asked and the sift criteria used to establish categories of severity are explained in the survey report (Grundy et al 1999). Topics covered include: employment and financial circumstances, use of health and social services and leisure activities. The survey results show that for younger adults (up to the mid-fifties) the prevalence of disability is higher for women than for men. Prevalence rates for Scotland were close to the Great Britain rates.

### Prevalence statistics

3.13 According to Census 2001 prevalence of limiting long-term illness in people of working age ranged from 11% to 24% by Council area in Scotland. The prevalence in Glasgow, at 21.68%, was considerably higher than the next highest – North Lanarkshire at 19.26%. The lowest rate was found in Aberdeenshire with East Renfrewshire a close second.

3.14 The SHS for 2001/2 counts 19% of adults (aged 16+) as having a disability or long term illness.

**Table 3.1 Adults aged 16-59 with a disability 2001/2 – percentage by age group**

Age	16-24	25-34	35-44	45-59	60-74	75+	Base
Disability	3	5	10	24	32	25	2,198
Disability and long term illness	1	3	10	27	38	21	1,211

Source: Social Focus on Disability 2004

3.15 In 2003 there were 7,500 registered blind and partially sighted people aged 16-64 in Scotland and an estimated 212,000 Deaf or hard of hearing people aged 16-60 (RNID statistics quoted in Social Focus on Disability 2004).

3.16 For Great Britain, an estimated 20% of the adult population had an impairment, with just over half (53%) of disabled people in the 16-64 age group. Prevalence of impairment was strongly associated with marital status and socio-economic characteristics such as housing tenure. For Great Britain, an estimated 20% of the adult population had an impairment with just over half (53%) of disabled people in the 16-64 age group. The 1996/7 disability survey reported that disability rates varied substantially by marital status and socio-economic characteristics such as housing tenure. Being married and having a higher household income were both associated with a lower likelihood of being disabled. Men in their 40s who lived in rented accommodation, for example, were four times more likely to be disabled than the equivalent owner-occupiers (Grundy et al 1998).

### Trends

3.17 Time series based on the Census are an important source of trend information, although of limited use for the immediate purpose because of the very broad 'limiting long-term illness' category used.

<sup>3</sup> 7000 adults were included in the first part of the survey which established severity of disability and led to a sample of 5000 who completed the second part which dealt with use of services, activities and need for help.

3.18 The SHS, the main statistical source for the household population in Scotland, is a relatively recent survey having started in 1999. Provided questions remain the same, this should prove a valuable source of time series on prevalence and use of services in future years. However for more in depth analysis linked to severity of impairment, the time series generated by the Disability Surveys for Great Britain would remain the best source, provided the survey is continued as before.

## THEMATIC OVERVIEW

### Key emerging issues overall

3.19 In the introduction to this report, we noted the definitions of ‘impairment’ and ‘disability’ used within the social model of disability. This locates disability within the material barriers and constraints facing disabled people in their everyday lives, arguing that action is needed to change the underlying structures, and to ensure that disabled people enjoy the same civil and political rights as anyone else. In contrast, the traditional medical model focuses on impairment at the individual level, with the emphasis on treatment, cure, rehabilitation and/or care. These differing models are important to this study because the perspective adopted in any publication – albeit implicitly in many cases – determines the way in which way issues are approached and presented.

3.20 A striking feature of much of the research and related evidence we have scoped is the absence of an explicit theoretical framework. Much is impairment specific, implying a medical model of disability. For example, some focus on individuals’ care needs: one study reported that people with visual impairment have mobility and communication problems *which can make it difficult to access services* while another stated that disabled people had experienced difficulty accessing goods, services and facilities *because of their impairments* (our emphases). Other authors conceptualise the challenges faced by disabled people in terms of barriers rather than individual need or deficit. Some studies tend to oscillate between different perspectives.

3.21 The research about early onset dementia is, generally speaking, embedded in a medical model. Until now, the social model has taken very little account of people with this condition. However, Beattie et al (2005) call for a discussion of ways in which society disables people with early onset dementia, arguing that it is time for the development of a ‘sophisticated sociology of impairment’ within the social model. As these authors point out, fuller incorporation of impairment into the social model has already led to discussion about the barriers facing people with learning disabilities (e.g.: Goodley 2004, Chappell 1992), and those with mental distress (Beresford 2002).

3.22 Barriers to meeting disabled people’s needs/ rights, and providing effective services, can be identified at a number of levels from the evidence reviewed. First, there are structural barriers, for example, in the form of housing, transport and the built environment.

3.23 Secondly, there are policy barriers, such as segregated schooling and lack of effective inclusion policies within further and higher education. Inadequate resourcing of services is also a recurring theme. The need for joined up policy to reflect the links between different areas of people’s lives is reiterated along with the benefits of a holistic, multi-disciplinary

approach, for example in assessing community care and housing needs. In this report, for ease of presentation, we have separated different topic areas but the frequent cross-referencing between sections illustrates the point. For example, transport-related exclusion affects disabled people's opportunities for participating in the labour market and their ability to access social and leisure activities. Another study suggested that tensions between housing, benefits, employment and health policies can lead people towards dependence rather than independence. The links between policy areas also interact with aspects of the individual's situation; thus, outcomes for young people approaching adulthood are said to be influenced by the interplay between impairment, family support and state intervention.

3.24 Thirdly there are service barriers, some of which may be the effects of policy barriers, others perhaps linked to problems arising at practice level. Much of the research relates to a particular type of service, reflecting the generally patchy and piecemeal nature of much provision for disabled people. Geographic variation within service provision across Scotland has been a recurring theme, for example in services for people with sensory impairment (see below), the implementation of care management, provision of equipment and adaptations and the availability of accessible housing and transport. The issue of rurality has received some attention in the research but not as much as might be expected within Scotland, given its particular geographic and demographic features. Delays and omissions in service provision have been identified, particularly in carrying out assessments and providing equipment and adaptations. There is also evidence about shortages of specific types of service.

3.25 Fourthly, there are barriers at cultural or attitudinal level. Entrenched cultures within some services and organisations can make professionals reluctant to share or give up power. Problems were identified in several studies in the attitudes to disabled people held by staff in various settings including leisure facilities, public transport and high street services. In addition, while public responses as polled in market research may be positive overall, other evidence shows a shocking level of hate crime against disabled people and the need for a public education campaign. The 'think tank' Demos is currently engaged in a 'disablism audit', collecting information on the discrimination faced by disabled people. It points out that data on this topic are fragmented and that disablism receives less attention than discrimination faced by other groups. The evidence scoped in this study points to the need for widespread Disability Awareness Training and Deaf awareness training, for service providers in all sectors and types of service, for school children and the public at large. This was a point which the SDEF endorsed and wished to be emphasised.

3.26 There are various other recommendations for staff training within the research, for example, transition planning for those working with young people, training in signing and providing good quality care for bilingual staff working with minority communities, and specialist training for those working with people with PMI, early onset dementia and alcohol-related dementia. It is important that disabled people are involved in delivering training wherever possible and appropriate.

3.27 Research about families and carers should, again, be seen in the context of the wider literature and relates, in part, to whether disabled people are seen as having civil rights or needing individual care. This is pertinent to the literature about 'young carers' which suggests that, were disabled adults given the rights and support services to which they are entitled, younger family members would not have to take on 'caring' roles.

3.28 Significant, although as yet unresolved, debates have been taking place within disability studies for some time about the place of personal experience and in particular the role and implications of impairment. Thomas (1999) developed the ‘social relational model of disability’, introducing the idea of ‘impairment effects’ to denote restrictions of activity resulting from living with a specific impairment. She also identifies a process called ‘psycho-emotional disablism’ which refers to hurtful, hostile or inappropriate comments or behaviour emanating either at the personal individual level or else resulting from exclusionary institutional policies and practices. Thomas stresses that disability is rooted in unequal social relationships, seeing it as a form of social oppression like racism or sexism. Her thesis appears to speak to much of the evidence uncovered in this study and could be seen as offering a fruitful theoretical framework for future research in this field. In terms of putting the social model into practice within services provision, the work of Jennifer Harris and colleagues at the Social Policy Research Unit at York University offers some useful pointers.

### **Service users’ perspectives and roles in decision making**

3.29 It is clear from the evidence as a whole that there is no one ‘user view’: disabled people are heterogeneous and differ from each other on many dimensions. There are different, and sometimes opposing, views and it is important to avoid over simplification or generalisation. In addition, research exploring the interaction between disability and gender, ethnicity and sexual orientation is still in its infancy.

3.30 Within the Scottish research scoped, there is limited general discussion about disabled people’s views. Research funders and policy makers are increasingly consulting disabled people about single studies or specific services but there is considerable scope for more active involvement of disabled people in setting the research and/or policy agendas across the board. At service planning/ management level, it was suggested in 1995 that disabled people were not systematically involved in planning processes for health and community care and, where they were involved, it was usually at the lowest tier and on a single impairment basis. It could be argued that the situation has improved considerably since then but there is limited research evidence to illustrate it. Recent studies indicate, for example, that more consultation is required between disabled people and transport providers, and that information held by housing providers seldom takes account of disabled people’s expressed views about their needs.

3.31 At an individual level, there are frequent reports of lack of accessible information about services and entitlements, and in some cases (generally relating to financial issues and benefit rules) a lack of understanding due to the complexities of the system. Disabled people’s accounts of social care assessments were not favourable overall. One (English) study described these experiences as ‘confused and fragmentary’. Practitioners failed to take account of the complexity and interdependency within many caring relationships and wanted to label one person as user and another as carer. In some cases, practitioners failed to involve disabled people in assessments and sometimes did not even inform them that an assessment was being carried out. Not enough effort is made to seek the views of people with sensory impairments during assessments.

3.32 Another recurring point is that disabled people’s views and priorities can differ from those of professionals, for example in relation to identifying and dealing with risk or making the transition to adulthood. Young disabled people, especially those with complex needs or

communication impairments, are not always consulted enough about post school options. The research suggests they are often keen to be active and independent, and to have access to youth culture and the arenas it occupies. Some professionals see transition more narrowly, however, in terms of slotting young people into adult services. The research suggests that practitioners are not always willing to take disabled people's priorities on board. They may tend to view disabled people as clients or service users rather than more holistically.

3.33 Disabled people have frequently emphasised that being able to make choices about, and exercise control over, their personal support, and thus over the rest of their lives, is a top priority. Flexibility and responsiveness of services are also very important. Higher levels of satisfaction are reported among disabled people where these features are present in services, direct payments being a prime example.

### **Key emerging issues relating to specific groups**

#### *People with early onset dementia*

3.34 Early onset dementia has been subject to limited research inquiries across the UK, particularly in Scotland. Much of what has been written about early onset dementia is confined to anecdotal accounts from practitioners about services they provide and their perceptions of any benefits such services may have for providers and users. Such accounts have been excluded from this scoping study. A recurring theme reported by authors reviewing the needs of people with early onset dementia is whether there should be separate specialist services for younger people with dementia or generic services, which are often services for older people with dementia (Tindall and Manthorpe 1997, Beattie et al 2002, SNAP 2000, Quinn 1996). Age appropriate services are often stressed as the way to develop good practice for early onset dementia, along with a range of appropriate services such as day care, pre and post diagnosis counselling, and ongoing assessment (O'Donovan 1999). Reports outlining the needs of people with dementia make reference to younger people with dementia for example, 'the rather different circumstances of younger people with dementia and their families require special attention, and will often need separate care arrangements (Alzheimer Scotland Action on Dementia 2000, 11). In addition the report of the Scottish Executive and Alzheimer Scotland short life working group 'Overcoming the Obstacles to the Improvement of Dementia Care' makes the statement 'The separate and distinct needs of younger people diagnosed with dementia should be recognised and not simply merged with services and arrangements more applicable to older people' (2004, 9). However the body of such reports is generally concerned with dementia generally rather than younger people specifically.

3.35 Thus, the challenges articulated by Alzheimer Scotland Action on Dementia (2000) facing those involved in the provision of services for all people with the condition are likely to be faced by those providing care for those with early onset dementia. Alzheimer Scotland Action on Dementia (2000) argues that assessment and diagnostic services responses, early stage responses, community care responses, long term care responses and palliative care responses for all people with dementia need better planning, with integration between agencies. They acknowledge that both specialist and generic services have a place. They also argue that more resources are required for dementia, a position echoed by others.

3.36 The studies about early onset dementia reviewed in this research reflect varying foci within the literature:

- a focus on all people with dementia (including early onset dementia)
- a focus on specific forms of dementia experienced by younger people with dementia
- a focus on younger people with dementia generally.

3.37 Thus there can be a tendency to report on services designed for all people with dementia, including younger people, which then make no specific reference to younger people.

3.38 The concern of much of the early onset dementia literature is to improve the services offered to both the person with dementia and their carers. Suggested ways to improve the support provided to people with early onset dementia are as follows:

- specialist services which provide well co-ordinated care which address primary need
- multidisciplinary working, including the integration of specialist workers into teams to give specialist advice
- consulting with service users about their views of services and their care needs to inform the development of appropriate services.

3.39 Finally it is important to contextualise the needs of, and services to, those with early onset dementia within dementia care generally. As Beattie et al (2005) remind us, younger people with dementia are difficult to fit into existing services, reflecting the general lack of specialist dementia services and a lack of appropriate day care and residential and nursing home services. Thus the general failure to meet the care needs of those with early onset dementia reflects the general marginalisation of all people with dementia within care services, compounded by the general under funding of services for people with dementia.

#### *People with sensory impairment*

3.40 While the study has identified a fair amount of evidence about the needs of, and services to, people with sensory impairment as a whole and the Deaf community specifically, there is less information about needs and services in relation to people with visual impairment and very little about individuals who are deafblind: basic information about their numbers and needs is not complete. In 2003, 7500 people aged 16-64 in Scotland were registered as blind or partially sighted and 212,000 people aged 16-60 as Deaf or hard of hearing. The last overview of their circumstances UK wide was 1996-7, so an update of that research is now required.

3.41 There is an ongoing debate about whether community care teams for people with sensory impairments should serve Deaf people, those with visual impairments and deaf-blind people, or whether there should be separate teams for people with different types of sensory impairment. Some service provision for people with sensory impairment is provided by local authorities and some is contracted out to the independent sector. Critics suggest this can lead to variations in the way assessments are carried out and thus, to inequities. Assessment arrangements have also been described as ad hoc and subject to delay. Unmet needs among people with sensory impairments include those related to information, communication support, rehabilitation support and advocacy. The Scottish Executive (2004a) has recently



published an Action Plan for services to people with sensory impairment to address some of these issues.

3.42 Both Deaf and visually impaired people face extra costs in their everyday lives. Deaf people can face particular problems accessing goods, facilities and services and also experience negative attitudes from a range of service providers. Deaf people within BME communities may be marginalised: one study claimed this was especially true of young Asians. There is little on offer to meet the needs of older Deaf people in BME communities.

3.43 The Scottish Executive is currently commissioning research about the community care and mental health needs of people with sensory impairment which should generate further useful information.

#### *People with profound multiple impairment (PMI)*

3.44 It is easy to forget that only a few years ago, many people with PMI would be living in long stay institutional care, sometimes in fairly grim hospital settings. There has been a remarkable – if overdue - change in the pattern and nature of service provision. Nearly all the social research in Scotland about people with profound and multiple impairment emanates from the White Top Research Unit at the University of Dundee. Hogg (1999) points out that there are still significant challenges in meeting the needs of people with PMI: they remain at risk of exclusion in many areas of their lives. He stresses the need for staff to be very proactive while working with this group, if they are to realise the potential benefits of ‘an ordinary life’ in the community. However, there is a gap between the research evidence now available and service delivery on the ground. There is information about choice, communication, understanding, ‘behaviour state’ (referring to relative levels of alertness), ‘challenging behaviour’ and growing competence: this knowledge needs to be incorporated in staff training. Health care needs among people with PMI are manifold and critical to a good quality of life. Again, these are better met now than in the past although it is suggested that a need for specialist as well as mainstream provision remains. Until recently, there has been a failure to pick up signs of mental distress among this population, but awareness is growing. Costs of provision for this group are generally higher than others.

#### *Disabled people from BME communities*

3.45 Information about the needs of and services to disabled people from BME communities in Scotland is limited, with small-scale studies tending to be impairment specific or confined to a particular geographic area – usually Glasgow, which has the highest population of people from BME backgrounds in Scotland. There is a lack of information about people living in rural areas. Although a few studies relate to particular ethnic minority groups, more often research tends to generalise about the needs of people from BME communities, without taking full account of the differences between the various communities, which to some extent affect perceptions of need, priorities and appropriate responses.

3.46 However it is clear from the research available that disabled people from BME communities are poorly represented in the labour market and encounter barriers in the benefits system. They lack awareness of and information about their entitlements and

available services, largely as a result of inaccessible information, and a paucity of translated material and interpreters. A lack of cultural sensitivity within services is frequently identified. It has been suggested that disabled people in BME communities have little contact with each other, suggesting they might benefit from being brought together either by Black community organisations and/or better included by existing organisations of disabled people which tend to be Eurocentric.

3.47 Evidence suggested that stereotypes persist about people from BME communities being looked after by their extended families and/or choosing not to make use of services. There is a shortage of particular types of support, including projects supporting young people, Black carers' groups, peer support groups and short breaks. The DRC/CERES has concluded that most services in the UK are not yet ready to 'take on board the complex needs of disabled people from BME communities'.

### *People with multiple identities*

3.48 There is very little information about disabled people with multiple identities in Scotland. One study (not conducted in Scotland) suggested that people with multiple identities viewed this in a positive light and believed that, overall, opportunities were improving for all disabled people. Elsewhere, however, there is evidence of discrimination and prejudice. Given the wide reach of feminist studies, it is surprising that, with a few well known exceptions of disabled feminists/activists who have sought to incorporate feminist debates within disability research, (Morris 1993, Thomas 1999) there has been relatively little work about disabled women's experiences. This is even truer for disabled men, despite growing interest in masculinity within sociology.

3.49 We were not able to identify any published research about LGBT disabled people in Scotland. However, funding has been agreed for one study, commissioned by Communities Scotland, to look at the role of disabled LGBT people within disability and LGBT agencies, and ongoing research elsewhere in the UK was noted.

### **Good innovative and user focused practice**

3.50 Some examples of 'good practice' projects were identified in the research but overall less evidence was found than anticipated. This does not mean there is a lack of good practice on the ground but much of it may not have been documented or evaluated. It is also possible that innovative user-focused projects are located within user or voluntary agencies and any reports about them may not be well publicised nor even in the public domain. Again, the timescale of the study did not allow the time that might be needed to 'root out' such documents.

3.51 At the same time, the literature reviewed did identify elements or principles of good practice in different areas and these are summarised below: The Prime Minister's Strategy Unit (2005) identifies the following principles of policy design:

- putting disabled people at the centre of policy design and service delivery
- adequate, timely and coordinated interventions
- meaningful choice for disabled people between services

- accountability to disabled people
- cost effectiveness
- joined up working
- in work with disabled people from BME communities, standard provision of translating and interpreting, accessible information, advocacy, targeted publicity and outreach work, consulting local communities
- in transition planning with young people, a multi-disciplinary, holistic, approach with the young person closely involved at all stages and given appropriate support for involvement, as well as information and choice about post school options; a focus on strengths not deficits
- in services for people with early onset dementia, age appropriateness
- n tackling barriers at times of transition such as from children's to adult services, from care settings to the person's own home, from living in one area to moving to another - joint assessments, multi-disciplinary teams, flexibility in health care and social services budgets, key working and evidence based practice.

3.52 The SDEF proposed a greater emphasis on the need for an easy mechanism to share good practice on a regular and informal basis.

### **Gaps in the evidence base**

3.53 It will not always be appropriate to address the gaps in the evidence base through disability specific studies. In order to promote an inclusive perspective, it will sometimes be more useful to include disabled participants within other research. For example, research about younger disabled people and transitions to adulthood could include some disabled youngsters and analyse their experiences both as part of the whole, and separately in order to identify any issues specific to them. This also avoids the need to have separate control or comparison groups built into studies which may be predicated on assumptions of difference rather than also looking for areas of similarity.

3.54 Over recent years, disabled people have been critical of research that fails to address their priorities, emphasising that they should be involved in setting the research agenda and questions and, where they wish, in planning and carrying out studies. The importance of giving feedback to participants, both about the findings of studies they have contributed to, and about any action taken as a result, in terms of policy/ practice developments, has also been stressed. The former is the responsibility of researchers and research commissioners, the latter of commissioners and service providers.

3.55 Some significant gaps have been identified in the current evidence base about disabled people in Scotland. Suggestions for further research on the various topics have been identified at the end of the relevant section and will not be repeated here. However, some areas stand out as having been little explored; others require research following major legislative or policy change. These are:

- the views and experiences of disabled parents, their strengths and support needs
- diversity, identity and active citizenship
- views of disabled people from Black and minority ethnic groups in Scotland about how best services can meet their support needs

- disabled men's support needs and experiences of services
- the views and experiences of disabled LGBT people
- costs (Only a handful of studies were identified which looked at the costs of assessment/ services, and in only one was that the main focus)
- outcomes of, and satisfaction with, different model of transition among young people with physical/ sensory impairment
- the impact and effectiveness of the newly implemented provisions of the Disability Discrimination Act 1995 affecting providers of goods, facilities and services and organisations with less than 15 employees
- the impact of the Special Educational Needs and Disability Act 2001 (SENDA) in tackling disability discrimination in education
- national overview of circumstances of people with visual impairment, the last (UK wide) survey being 1996/7
- the numbers, circumstances, needs and views of deaf-blind people
- disabled people's experiences of assessment following the introduction of Single Shared Assessment procedures
- carers' experiences of assessments following the implementation of the Community Care and Health (Scotland) Act 2002
- the views and experiences of disabled people about adult education, community education and lifelong learning.

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## APPENDICES

### APPENDIX 1: Glossary

The report contains a number of acronyms, explained below:

AAC: Augmentative and alternative communication

ASAD: Alzheimer Scotland Action on Dementia

BME: Black and minority ethnic

CANDID: Counselling and Diagnosis in Dementia: see <http://dementia.ion.ucl.ac.uk/CANDID.htm>

CERES: Centre for Education for Racial Equality in Scotland, School of Education, University of Edinburgh

CHSR: Centre for Health and Social Research, University of Newcastle

DDA: Disability Discrimination Act 1995

DRC: Disability Rights Commission

DSS: Department of Social Security

DWP: Department for Work and Pensions

OECD: Organisation for European Co-operation and Development

PMI: Profound multiple impairment

RNIB: Royal National Institute for the Blind

RNID: Royal National Institute for the Deaf

SCARE: Social Care Access to Research Evidence (research briefings produced by SCIE)

SCIE: Social Care Institute for Excellence

SCROL: Scottish Census Results on Line

SDEF: Scottish Disability Equality Forum

SHS: Scottish Household Survey

SNAP: Scottish Needs Assessment Programme

SWSI: Social Work Service Inspectorate, Scottish Executive

**APPENDIX 2: Data Entry Form Used in Scoping Study**

Originator: (i.e. reviewer's name)

Year:

Title:

Author:

Publication Details:

Topic (as defined by the authors):

Population:

Type of study:

(Lit. review; survey; secondary analysis; qualitative; evaluation; other)

Population

Key Findings:



\* Please mark applicable boxes below with 1

N/A	Scotland	Local Scotland	Rural Scotland	UK	Other (please specify)

Sector

N/A	Statutory	Voluntary	Private	Independent	All sectors

Topics covered (as our tick boxes on database)

Equality and diversity	Transition	Early onset Dementia	Unmet need	Needs Assessment	Social Care	Housing
Residential	Informal	Benefits	Transport	Technology	Education	Other
Goods and services	Employment	Profound multiple impairments	Health care	Aids/adaptations		

Review	Statistics

Good practice	User perspective

**APPENDIX 3: Letter Sent to SDEF from Tweeddale Access Panel in Response to Request for Information Relevant to this Study**

**TWEEDDALE ACCESS PANEL**

CHAIRMAN-STEWART REGAN, 7 THE LOANINGS, PEEBLES TEL. 01721 720416  
SECRETARY-JANETTE COOK, 4 SOUTH PARKS, PEEBLES TEL. 01721 723191

Dear Wyn

I am writing in response to your letter requesting to identify the needs of disabled people, for Applied Social Science at Stirling University research.

We as a Panel feel disabled people are still experiencing second class service and encountering major problems nationally in the High Streets.

A survey for the D.R.C., of twelve major high streets across the country shows that majority of shops, cafes, restaurants, cinemas and pubs are still problematic for disabled people, many retail outlets have not made substantial improvements to comply with D.D.A. which came into effect on 1st October 2004.

It's clear some shops and services are getting their act together for the disabled consumer but there are those who have done little or nothing to prepare for the legislation coming in.

Public Transport: it has a long way to go before it can fully service the disabled public particularly in rural areas, the few accessible buses on our roads are not timetabled on routes they service, you could find yourself with an accessible bus on your outward journey and be stranded for the homeward journey when a stepped platform vehicle turns up, if you are lucky to find an accessible bus there will be no restraints fitted for wheelchair users.

Demand responsive transport initiatives are crucial, better disability awareness training for all transport staff nationwide needed now!

If you can't use public transport it means your chances of getting and maintaining a job, accessing health care, seeing your friends and family and leading a normal life are significantly reduced.

I do hope the issues raised will be constructive to you and whoever you may pass this on to.

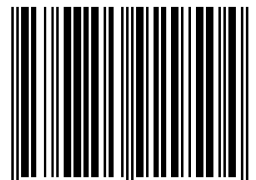
Yours sincerely

Stewart Regan

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