A Literature Review on
Multiple and Complex Needs

Social Justice

A LITERATURE REVIEW ON MULTIPLE AND COMPLEX NEEDS

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Closing the Opportunity Gap Approach
Multiple and Complex Needs

The views expressed in this report are those of the researchers and do not necessarily represent those of the Department or Scottish Ministers.

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EXECUTIVE SUMMARY

STUDY AIMS

1.   Given the increasing attention to 'multiple and complex needs' in policy and practice, the aim of this research was to review the evidence from the research literature on service provision for people with multiple and complex needs. Five key objectives of the literature review were: to examine definitions of 'multiple and complex needs' and to identify client groups who are identified as having these needs; to explore people's awareness of services and options; to explore factors affecting access to services; to examine service users' experiences; and to identify best practice in service provision and lessons for implementation.

METHODOLOGY

2.   The wide range of potential groups to be covered and the diversity of services to address their needs, required the literature review to focus on: literature covering multiple and complex needs from Scotland and the UK since 1999; existing reviews and summaries of findings; good practice guidance issued by the Scottish Executive and UK Government Departments; published and grey research literature, including needs assessment reports and research identifying both service user experiences and barriers to accessing services or gaps in these. Before conducting literature searches 15 key informants were consulted, and, during the project, a focus group was conducted with research and policy staff within the Scottish Executive in March 2006.

3.   Searches of relevant databases, internet sites and publication search sources were carried out in 2 stages. The initial trawl of literature sought to identify definitions of multiple and complex needs from the literature. The subsequent phase of searches broadened the focus to address the wider research interest in service pathways in terms of the experience of people with multiple and complex needs in terms of 'getting into services, getting on within services and getting through or moving on within and through services. Additionally the review sought to clarify associated best practice.

4.   Given the diversity of the material covered and the breadth of its focus this review makes no claim to full comprehensiveness in tackling the subject of meeting the needs of people with multiple and complex needs (however defined), but it did strive to identify systematically the key themes running through the literature.

5.   The review covered 3 broad categories of literature that address multiple and complex needs, which overall focus on overlapping themes. First there was a body of literature that explored service and policy implications of issues of multiple and/or complex needs, much of which focused on particular client groups. Secondly, a larger body of literature used the terminology of multiple and complex needs but did not focus specifically on related policy and practice implications. Thirdly, a far wider body of literature was referred to that addressed relevant themes without explicit use of the terminology of multiple and/or complex; rather they referred to 'multiple disadvantage', 'multiple problems' or 'severe exclusion' and linked this with the context of poverty, dependence on welfare benefits, and the impact of homelessness, serious health problems and impairment, literacy problems, substance misuse, criminal justice issues and/or in some instances, institutionalisation and leaving institutions. Overall the study focused mainly on the first 2 groups of literature.

KEY FINDINGS

Multiple terminology

6.   A plethora of terms are linked with the concepts of 'complex' and 'multiple' needs, used by various disciplines, sometimes specifically, and often interchangeably. They include: 'multiple disadvantage', 'multiple disabilities', 'multiple impairment', 'dual diagnosis', 'high support needs', 'complex health needs', and 'multiple and complex needs'.   This multiple usage was confirmed by preceding reviews carried out by Rankin and Regan (2004) and Keene (2001).   Rankin and Regan usefully identified the essence of complex needs as implying both *breadth of need* (more than one need, with multiple needs interconnected) and *depth of need* (profound, severe, serious or intense needs). Additionally, they use the term 'complex needs' as "a framework for understanding multiple, interlocking needs that span health and social issues".

Who has multiple and complex needs?

7.   A very wide range of people were identified as having multiple and complex needs. These included:

- People with mental health problems, including 'severe and lasting' problems
- Those disadvantaged by age and transitions – young and older people
- Those fleeing abuse and violence – mainly women and refugees
- Those culturally and circumstantially disadvantaged or excluded - minority ethnic groups; travelling people
- People with a disability, including profound, severe or long term impairment or disability and those with sensory disabilities with 'additional needs'
- People who present challenging behaviours to services, for example in schools, within residential services/ hostels or in their own neighbourhoods
- People who are multiply disadvantaged by poverty, poor housing, poor environments or rural locations which mean they are distant from services
- People who are 'marginal, high risk and hard to reach', who may be involved in substance misuse, offending and at risk of exclusion (Watson, 2003)
- People who have a 'dual diagnosis' of mental ill health and substance misuse, or of other combinations of medically defined conditions.

Key patterns in service responses

8.   Chapters Three and Four of the report focused on how people with multiple and complex needs fare in terms of awareness, access and experience of the services that they need. Some key problems identified included:

Awareness: There was regular identification of a lack of or inaccessible information, poorly advertised services and low awareness of what services can offer.

- People from black and minority ethnic communities, refugee and asylum seekers face particular difficulties in accessing information and advice
- There are shortfalls in interpretation and translation services and a lack of awareness among individuals and agencies about how to access these
- Other groups with multiple and complex needs, such as people with dementia, people with sensory impairments (Scottish Executive, 2003b), and people with multiple and profound intellectual disabilities also often do not know what services there are and face barriers to accessing services

- Current advice services tend to treat problems in isolation; advice can be hard to access and referral mechanisms inefficient
- Many people, including people with additional needs and their carers, are daunted by complex service systems.

Accessing services:
- Many people with multiple and complex needs do not gain access to the services they need or end up in inappropriate services
- Poverty and inequality impact on disadvantage in accessing services, while low aspirations (by professionals and service users) also limit opportunities
- Disabled people generally experience significant barriers to access
- People with multiple and complex needs may be excluded from services because of criteria governing service use (e.g. age restrictions)
- Some targets undermine the will to work with clients with multiple needs
- Lack of referrals between agencies and inappropriate referrals limit access
- Long waiting lists worsen problems for those with multiple/complex needs.

Experience of services:
- People with multiple needs may be 'defined out' or excluded from services for organisational reasons, e.g. their needs are assessed as 'too complex or challenging' for the service(s) in question
- Some feel staff attitudes are insensitive and unhelpful which prevents trust
- Inflexible service criteria (eg. age cut off points) prevent continuity of care
- Service users and carers are often unaware of entitlements to assessment
- Many receive repeated assessments which is stressful
- A 'silo mentality' works against co-ordination of support and risks people receiving inappropriate services with poor outcomes
- Medical 'dual diagnosis' labels limit the range of options
- Assessment, support planning and resources can be inadequate for people affected by transitions, thus delaying access or limiting people's rights
- When service users and carers disagree with professionals' assessments, options appear to be constrained by resources or limited vision
- People from minority ethnic communities, refugees and asylum seekers do not always receive sensitive assessment or access interpreters and translators
- Non-engagement with services occurs because of dispositional, organisational, situational and structural factors, including: lack of trust and confidence, cultural insensitivities, services' systems or cultures being incompatible with life-styles, poverty impacts, and people not being ready to address problems. In turn, non-engagement may exacerbate low level problems and exclusion. For some, persistent exclusion may result, interspersed with crises related to health or homelessness for example.

Summarising the constraints and exploring what service users want
9.   Overall the research highlights that:

- At government level there is a lack of strategic prioritisation and fragmentation, while local commissioning systems are often fragmented
- Local service networks may involve lack of co-ordination and poor information flow, a lack of support for participation, agency divides and culture clashes

- At service level, responses may be limited by narrow vision; short-time frames, crisis-driven assessment and communication blocks
- Wider constraints on positive responses include stigma and resource constraints.

GOOD PRACTICE AND LESSONS FOR IMPLEMENTATION

10. While people with multiple and complex needs appeared to be significantly disadvantaged, the service responses they valued were broadly similar to those valued by service users in general. They range from person-centred approaches that treat people with respect and sensitivity, to the scope for accessing appropriate and responsive services in a co-ordinated way (Chapter Five). Moreover, a significant range of good practice was identified in Chapter Six. This included:

- Targeted and outreach information provision in accessible formats
- Single access points and 'one stop approaches'
- Services that address 'whole person' needs and do so in partnership
- Personalised and person-centred service responses
- Co-ordinated and integrated assessments
- Outreach services that seek out and stick with 'hard to reach' groups
- Community development and empowering approaches, such as peer education, that promote participation and engagement
- Professionals with a remit to link and co-ordinate support services such as key workers, link workers or service navigators can help minimise the impact of service fragmentation
- Creative examples of joint work, partnerships and joint training.

Beyond the good practice identified, the policy developments and practice guidance covered in Chapters Six and Seven emphasise the following:
- Support, care or pathway plans as useful tools for moving forward
- IT and information sharing
- Involving service users (and carers) at all levels of service planning, development and delivery, alongside access to advocacy
- Recognition in target setting that 'soft' rather than hard or quantifiable outcomes may be most appropriate for clients with multiple/ complex needs.

11. Key elements of good practice are outlined further in Chapter Seven and Appendix 3, including in regard to:

- Partnerships and agencies developing strategies to target improved responses to people with multiple and/or complex needs
- Developing more innovative and imaginative joint approaches
- Targeted information and advice about services
- A range of approaches and resources including highly supported longer-term accommodation
- Access to direct payments
- Maximising participation and involvement and access to advocacy
- Committed, creative approaches to resource pooling.

12.	Finally, this study found that multiple needs affect a wide range of people to varying degrees and with varying consequences. Overall, while the report illustrates a variety of excellent practice, more generally it presents a bleak picture of the quality of responses obtained by people with multiple and complex needs, who continue to be significantly disadvantaged and excluded. It emphasises significant gaps in services and support and stresses the need for more innovative and creative joint strategies, as well as partnerships that involve service users in increasing the effectiveness of the service response. It recognises that some people will not be ready to engage with what is on offer, but urges persistence. It also recognises significant shortfalls in funding that must be addressed to meet needs.

CHAPTER ONE: INTRODUCTION

BACKGROUND

1.1.   The primary motivation for the literature review came from the Scottish Executive's commitment to assessing the impact of multiple and complex needs and how a range of services can respond effectively, taking account of recent and ongoing national developments that are relevant to good practice. The study was commissioned to complement 2 current strands of work within the Scottish Executive:

1. Analysis by the Office of the Chief Statistician to explore the prevalence of particular needs and combinations of need among people belonging to various social groups

2. A funded series of pilot/demonstration projects to address multiple needs in relation to specific sectors, such as health and social work services, and the monitoring and evaluation of these projects.

1.2.   The literature review is set against the backcloth of recent developments in social policy and related agendas and streams of work:

- The 'personalisation of services' agenda (Leadbeater, 2004)
- Developing better public services in Scotland through the Modernising Government Fund (Scottish Executive, 2003a; Scottish Executive, 2006a)
- The Social Exclusion Unit in the Office of the Deputy Prime Minister's (ODPM) work on 'Improving Services, Improving Lives' project, and
- Proposals on the provision of social care to people as defined in '*Meeting Complex Needs: The Future of Social Care*' (Rankin and Regan, 2004).

1.3.   It is worth highlighting at the start that The Social Exclusion Unit has turned its attention to issues of multiple and complex needs and has noted that:

> *"Effectively meeting the needs of disadvantaged people – particularly those with the most acute/and or multiple needs can be expensive. In the context of increased efforts to make efficiencies, we need to develop the best possible understanding of the economic and ethical cases for investing in more intensive and longer-term support for those who need it."* Social Exclusion Unit, 2005a, p16).

AIMS AND OBJECTIVES

1.4.   The overall aim of the review as commissioned was to identify, organise, evaluate and summarise key evidence from the research literature on a range of issues relevant both to service provision and to people with multiple and complex needs.

1.5.   Further, the study had 5 key objectives, which were to:

1. Identify and define 'multiple and complex needs' and the groups most likely to require support

2. Explore awareness of services and options

3. Explore factors affecting access to services

4. Examine users' experiences of service provision

5. Identify best practice in service provision and lessons from implementation.

RESEARCH METHOD

1.6.   Given the scope and range of services (from health and social work to legal and financial services) and potential groups (e.g. people with disabilities, people with low incomes and minority ethnic communities) to be considered within the terminology of 'multiple and complex needs', the size of the literature base on this topic is potentially infinite. In an attempt to limit the scope of the literature review to a manageable task within the short timeframe it was decided to focus in the main on:

- Literature on multiple and complex needs from Scotland and the UK, which was published within the past 5 years, i.e. since 1999

- Existing reviews and summaries of findings wherever possible

- Good practice guidance issued by the Scottish Executive Departments, Communities Scotland, the Office of the Deputy Prime Minister, Department of Health and other governmental departments

- Published and grey research literature including needs assessment reports, which refer specifically to multiple and/or complex needs in relation to areas of the research framework

- Research findings identifying both service user experiences and barriers to services or gaps.

Identifying relevant literature

1.7.   An initial step in searching the available literature involved consulting key informants and organisations, in addition to conducting systematic reviews of library and on-line catalogues and databases. Given the interest in ensuring key relevance to Scotland and to policy and practice, 15 key agency representatives and/or individual 'experts' were contacted by email and telephone. A small number of face-to-face interviews also took place and a

focus group was held with research and policy staff within the Scottish Executive in March 2006.

1.8.   These included academics from a range of disciplines (disability, dementia, social policy, faiths and religion) at Edinburgh, Strathclyde, Stirling, Dundee and Ulster Universities as well as housing and community care organisations (including Community Care Providers Scotland, Turning Point Scotland. Homeless Link, Scottish Refugee Council). The interviews sought to investigate:

- Definitions of multiple and complex needs
- Whether issues of multiple and complex needs had emerged as a specific concern in their field or organisation
- Main client groups defined as having multiple and complex needs
- The key issues in terms of access to services, pathways in and through services
- Key implications for practice and policy
- Informant's knowledge of grey literature or key published documents to review
- The importance of focusing on multiple and complex needs.

1.9.   Searches of relevant databases, internet sites and publication search sources were carried out in 2 stages: the initial trawl of literature sought to identify definitions of multiple and complex needs from the literature, whilst subsequent searches broadened this search to literature relating to the wider research framework that focused on service pathways and best practice. The focus on service pathways centred on the experience of people with multiple and complex needs in terms of 'getting into services, getting on within services and getting through or moving on within and through services'. Additionally the review sought to clarify associated best practice. Given these concerns, tables will be presented that summarise chapter findings at the end of Chapters Three, Four and Five, in relation to the stage of the service pathways covered, related processes and influencing factors and implications for service responses.

1.10.   The searches identified below were conducted to maximise the scope of the review.

Table 1.1.: List of main databases and indexes sourced for the literature review

Library database/Index	Publisher	Journals	Internet websites	Government sites
IngentaConnect	Pavilion Press	Community Care	Joseph Rowntree Foundation	Scottish Executive
IDOX/PLANEX	Policy Press		DEMOS	Department of Health
Applied Social Science Index and Abstracts (ASSIA)	Jessica Kingsley	British Journal of Social Work	Turning Points	ODPM/Social Exclusion Unit
Google Scholar		Health and Social Care in the Community	Terrance Higgins Trust	Department for Constitutional Affairs
Social Care Institute for Excellence SCIE/ Social Care on Line		Journal of Integrated Care	Institute of Public Policy and Research (IPPR)	Valuing People
Science Direct			Revolving Door Agency	
Community Care Works University of Glasgow			Kings Fund	

1.11. Keywords including 'complex needs', 'multiple needs', 'multiple and complex needs', 'multiple disabilities', 'multiple impairment', 'multiple disadvantage' and 'dual diagnosis' were used to search the databases at Edinburgh and Glasgow University libraries, the National Library for Scotland and online databases. In later searches these were combined with keywords representing aspects of service pathways (awareness, access, user experiences, outcomes) and best practice (e.g. joint working, partnerships, holistic, person centred, one stop). In addition, reference and bibliography lists in key documents were scanned for further useful materials.

1.12. Two team members conducted the main searches of the literature, while all team members conducted reviews and produced summaries on each item reviewed. The literature covered was recorded, summarised and classified in terms of:

- Focus on particular client groups, policy and practice in Scotland, UK or wider
- Method – qualitative or quantitative
- How multiple and complex needs are addressed
- Definition of multiple and complex needs and related issues
- The focus on service user/non user pathways and experience
- Gaps, deficits and constraints identified
- Implications for policy and practice and
- Other relevant themes.

1.13. Key themes across the whole of the literature reviewed by each consultant were identified and discussed as the work progressed. This added to a cumulative analysis across all the literature and reflects the aims and objectives of the study.

THE SCOPE AND LIMITS OF THE STUDY

1.14. The lack of consensus and consistency within the literature on defining multiple and complex needs posed a major challenge to determining the search parameters for the literature review. Additionally, the broad approach required meant that it was not possible to cover all areas in depth within the timeframe. While the research team have not intentionally left out material relating to specific groups or service responses, the review cannot claim to have achieved full comprehensiveness, or to have treated all the literature equitably. Overall however, it did strive to identify systematically the key themes running through the literature and to reflect where the balance lies within the literature.

1.15. On the scope and approach of this review, it is important to clarify that rather than focus on exploring multiple and complex needs from the starting point of particular needs groups (such as mental health, learning disability, older people, those in contact with the criminal justice system, or people with particular conditions), it was resolved to focus on common strands of experience in the context of wider constraints and opportunities for people with multiple and complex needs.

1.16. The broad approach required meant however that it was not possible to cover some areas in depth within the timeframe. While the research team have not intentionally left out material relating to specific groups or services, the review does not claim to be comprehensive and does reflect where the balance lies within the literature. There may therefore be inequitable treatment of some areas of literature.

1.17.   Overall we found 3 broad categories of literature that addressed multiple and complex needs, which more or less, and from different perspectives, covered overlapping themes. The first group consisted of studies that addressed the service and policy implications of issues of multiple and/or complex needs. A minority of these studies provided an overview of the issues for people with multiple and complex needs, while most specifically addressed the multiple and complex needs of a defined client group. While certain studies offered very useful insights and leads in relation to the aims and objectives of this study, it was found that many studies did not systematically focus on people's pathways through services, which was a key focus of this research.

1.18.   The second was a larger body of literature which used the terminology of multiple and complex needs, but this focus was not central to the study. Most relevant policy reviews and reports did not surface through initial literature searches, but required searches on a range of web-sites. The third was a far wider body of literature that this study could not quantify or address systematically, that addressed equivalent themes to those covered by the first 2 groupings, but without explicit use of the terminology of multiple and/or complex needs. Examples included where authors used terms such as 'multiple disadvantage' or 'severe exclusion' and then referred to the consequences of significant poverty and dependence on welfare benefits, coupled with the impact of homelessness, serious health problems and impairment, literacy problems, substance misuse, criminal justice issues and/or in some instances, institutionalisation and leaving institutions.

1.19.   While this review has mainly focused on the first two categories of literature, where the research team was aware of other directly relevant material in the latter category, which shed light on access issues or pathways in and through services, or on good practice implications, this has been referred to and considered.

1.20.   Another point that should be acknowledged is that, in the main, the literature reviewed represents published material based on academics and professionals' perspectives. Some of this represented 'grey' literature, including agencies' reports accessed directly or on the web. Overall it appeared that this could offer a fruitful source of description and insights, although it was not feasible to tap this theme comprehensively within the time available for this project.

1.21.   One key point was that while Social Exclusion Unit reports and some Scottish Executive reports accessed have addressed multiple and complex needs building on the perspective and voice of service users, this was a clear gap in the overall literature.

STRUCTURE OF THE REPORT

1.22.   Chapter Two addresses the task of defining multiple and complex needs and it considers their prevalence. While the relevant literature draws on a number of perspectives, disability and social justice perspectives dominate. Chapters Three and Four review a range of literature covering pathways into and through human services, while Chapter Five focuses on summarising the gaps in services and clarifying what service users want. Chapter Six presents findings from the literature relating to ways of addressing the gaps and improving service responses to people with multiple and complex needs. Finally, Chapter Seven draws together the main themes raised through the literature review and discusses the implications of these themes for Scottish policy and practice.

CHAPTER TWO: WHO HAS MULTIPLE AND/OR COMPLEX NEEDS

INTRODUCTION

2.1.   This chapter first considers how the terms 'multiple' and/ or 'complex' needs have been defined and applied, primarily to clarify the client groups whose needs are of concern to this study and to identify key emergent themes. We then consider what some of the literature tells us about the prevalence of multiple and complex needs. This will set the context for exploring aspects of service pathways, gaps and best practice in meeting the needs of people with multiple and complex needs in subsequent chapters.

COMPLEX TERMINOLOGY AND MUTLIPLE ISSUES

2.2.   A plethora of terms are linked with the concepts of 'complex' and 'multiple' needs, used by various disciplines, sometimes specifically, and most often interchangeably. They include: 'multiple disadvantage', 'multiple disabilities', 'multiple impairment', 'dual diagnosis', 'high support needs', 'complex health needs', and 'multiple and complex needs'.

2.3.   Overall the review of the literature and our consultation programme points to a lack of consensus on the meaning of the various terms associated with 'multiple' and 'complex' needs. Often there was an assumption that complex and/or multiple needs are a matter of fact and can be understood without definition, and a strong thread through the literature was that the terms are used interchangeably.

2.4.   Having arrived at a similar conclusion, Rankin and Regan (2004) usefully identify the essence of complex needs as implying both:

- *breadth* - multiple needs (more than one) that are interrelated or interconnected
- *depth of need* - profound, severe, serious or intense needs.

2.5.   Rather than use the term 'complex needs' to *describe* an individual's characteristics, Rankin and Regan (2004) define it in terms of an *active framework for response*. These authors suggest the term offers:

> *"A framework for understanding multiple, interlocking needs that span health and social issues. People with complex needs may have to negotiate a number of different issues in their life, for example learning disability, mental health problems, substance abuse. They may also be living in deprived circumstances and lack access to suitable housing or meaningful daily activity. As this framework suggests, there is no generic complex needs case. Each individual with complex needs has a unique interaction between their health and social care needs and requires a personalised response from services."* (p 1)

2.6.   Rankin and Regan's inclusive approach leads us to consider how current service arrangements and the factors of poverty and exclusion impact on meeting multiple and complex needs. Moreover, they argue that social care should be brought within the social inclusion agenda. Neale (2004) similarly stresses that people's problems cannot be divorced

from structural factors, such as poverty, unsuitable housing, limited education and poor employment prospects.

2.7.   Below we illustrate the range of needs and issues highlighted and how these have been described and classified by those using the terminology of "multiple and complex needs".

Breadth and depth of need - 'multifaceted and multiple problems'
2.8.   These include people with mental health problems (Keene, 2001), young people, people with a disability (Mattingley, 2002), and *"people labelled with severe or profound impairment(s).   They are likely to have a range of different needs and to require support from several different services to meet these needs"* (Weston, 2000). Additionally, multiple needs have been identified for homeless people, travelling people, refugees and asylum seekers and people who have experienced violence or abuse (for example, Rosengard et al, 2000; Bevan 2000a, and b; Harrison, 2001; Social Exclusion Unit, 2004a).

Depth of need - 'profound, severe or long term impairment or disability'
2.9.   Those identified as having profound difficulties include people with severe and complex learning disabilities and non-verbal communication (Kellett, 2005; McIntosh and Whittaker, 1998); people with 'severe and lasting mental health problems' (Cunningham and McCollam, 2001) and people with sight disabilities or who are blind and have 'additional needs' (RNIB, 2001).

Presenting multiple problems to services
2.10.   The Social Exclusion Unit (2005b, p27) found that 98 percent of services that work with young people consulted in a survey, "said that young people presented to a particular service with multiple problems". Similarly Gross (2002) in relation to children with complex needs in ordinary primary schools links complex needs with behaviour problems and implications for teaching practices. Bowen et al (2002) link complex needs with severe or long term additional needs in education, and Bond (2004) connects complex needs with 'challenging behaviour'.

Multiple disadvantage
2.11.   Various commentators and Government reports highlight the links between high deprivation, area concentrations of poverty, unemployment, poor housing, problems with literacy and high risks of the impact of crime (Pantazis, Gordon and Levitas 2006; Social Exclusion Unit, 2005a and b; Scottish Executive 2005h). Rural location was found to exacerbate problems for people with complex needs (McCann et al 2005). Additionally, travelling people may only have access to poor quality sites, while some have literacy problems, disabilities and health problems, which may be exacerbated by frequent evictions (Morris and Clements, 2001). LGBT people frequently face problems caused by multiple disadvantage associated with their sexual orientation as well as with other factors such as race, disability, faith, economic or asylum status (Inclusion Project, 2003).

Multiple needs relating to age and transitions
2.12.   The research has focused on the multiple and complex needs of young and older people, including at points of transitions, such as leaving home, leaving institutions, or the onset of illness or disability. For example, Barlowe and Breeze (2005) explored the potential for teleshopping to alleviate problems of disability and isolation for older people for the Rowntree Foundation. The Social Exclusion Unit (2005b) defined young people with

complex needs as suffering "disproportionately from a number of different types of disadvantage, the impact of which results in challenges for service provision". Here disadvantage may include: worklessness, lack of training or education, poor health (in particular, mental and sexual health) or substance misuse.

People who are excluded and 'hard to reach'

2.13.   Many studies researching multiple disadvantage and people's support needs have identified a small population who have significant unmet needs (for example, Adebowale, 2004; Watson, 2003; Keene, 2001). Watson refers to people who are 'marginal, high risk and hard to reach'.

2.14.   This includes some young people who may be involved in substance misuse, offending and at risk of exclusions. Melrose (2004) identifies the complex needs of young people who are using substances and who have offended, been excluded from school and/or been looked after in the local authority care system. Serious substance misuse is seen as related to the "extreme vulnerability" to exclusion, exploitation and injury, of for example, young people involved in illicit drug use in Glasgow (Neale, 2004) or to the risk of homelessness and/ or exclusion from services for older people with chronic alcohol problems or alcohol related brain damage (Cox et al, 2004), or for younger people using substances.

2.15.   The 'Mind the Gaps' report by the Scottish Advisory Committee on Alcohol Misuse (SACDM and SACAM, 2003) refers to "deep-seated and multiple problems which often have complex and multiple causes" SACDM and SACAM state:

> *"'Mind the gaps'" is a report about "people with deep-seated and multiple problems which often have complex and multiple causes" (p11)…"The evidence also shows that people who experience co-occurring substance misuse and mental health problems often experience other complex social problems, such as unemployment, homelessness, violence and childhood trauma which can occur over long periods of time" (p12).*

2.16.   In sum the literature leads this review to focus on people with additional rather than singular needs, on the wider situational and structural influences on these needs, and on the effectiveness of service responses. Just as Stalker et al conclude from their study of the experience of children and young people with complex needs in hospital settings, there is no consensus of definition within the literature, nor amongst professionals, but rather *a surplus of meaning* (Stalker et al, 2003). Weston (2000) similarly comments that the term 'complex needs' is potentially ambiguous and contentious.

Note on implications of the terminology for the study report

2.17.   Against this background, in this report we shall apply the terms 'multiple' and 'complex' needs to signify both breadth and depth of need. It is worth noting that one concern that arose for the research team was the issue of whether describing people as having 'complex needs' may be stigmatising. However while the research team considered replacing the term 'complex needs' with that of 'additional needs', it was felt that this would potentially be confusing given the common usage of the term 'complex needs' within the literature.

EMERGENT POLICY CONCERNS AND PRIORITIES

2.18.   A strong thread running through the literature on multiple and complex needs is that service users identified as having multiple and complex needs are seen to be particularly poorly served by services. Some writers are concerned about this from a social justice and social inclusion perspective. Others appear to be driven by concerns that these groups are at the extreme end of a continuum of need and pose the greatest challenges to services.

2.19.   Concerns about service responses to multiple and complex needs have an international dimension, as was illustrated by a recent report on pilot projects in Australia that were specifically designed to improve outcomes for people with 'multiple and complex needs'.

2.20.   This raises issues that are relevant to the current Scottish Executive initiative involving the launch of several pilot projects in 2006. However it is important to note that the focus of the Scottish initiative differs in one important respect, which is that the range of pilot projects addresses a far wider spectrum of needs.

2.21.   The Australian agenda generated 2 reports by the Department of Human Services (2003a, and b) and a literature review on responding to people with 'high and complex needs' (Thomson Goodall Associates, 2002).   These focus on a clearly defined minority group whose needs have been identified as extremely challenging to services and who often experience inappropriate service responses. The rationale for the Australian pilot projects was identified thus:

> *"Over the past few years there have been concerns raised by service providers, clinicians, carers…regarding the difficulty in providing services to a group of people who have multiple and complex needs. These individuals include adolescents and adults who may experience various combinations of mental illness, intellectual disability, acquired brain injury, physical disability, behavioural difficulties, social isolation, family dysfunction and alcohol or other substance abuse.   Often they are unable to sustain appropriate accommodation, or require a level of support the current design of services does not readily allow. Services are often unable to maintain involvement over time with individuals with extremely difficult behaviours."*
> (Department of Human Services, 2003a, p5)

2.22.   Using case finding and a nomination process to identify target individuals combined with case studies of a sample of the target group, the Australian pilots identified and quantified the target group, and looked at people's service experiences, gaps in services and proposed solutions.

2.23.   Multiple and complex needs were defined in this literature as:

> *"Presenting factors that characterize the target population were a combination of all the following –*
>
> - *Having multiple and complex presenting problems*
> - *Having high and complex needs, not met or sustained by existing services*

- *Having challenging behaviours that place individual at high risk to self, service staff and/or the community*
- *Chronic or episodic behaviours and/or conditions that require long term service responses*
- *Requiring a service response from 2 or more department programmes (or criminal justice) areas*
- *Having a specific need for which there is no current service system response and/or require a current tailored funding package (usually at high cost)."*

2.24. While this definition is clearly at odds with the framework proposed by Rankin and Regan (2004), it suggests a continuum of need and complexity, as is increasingly found in the policy and other literature. For instance, both the 21st Century Review of Social Work (Scottish Executive, 2006b) and SACDM and SACAM (2003) adopt this definition.

2.25. Keene (2001) in a research based, literature and analytical overview in relation to 'clients with complex needs' (which incidentally was used to inform the Australian approach), chose to focus on "the most difficult and intractable group who make heavy use of services". At the other end of the spectrum of need are considered to be people with a single 'simple need'. Again this implies a hierarchy of need reflected in patterns of use and challenges to services. In examining clients with complex needs, Keene focuses attention on:

> *"Vulnerable men and women with complex health, psychological and social problems who move more or less continually through social, mental health and health care agencies, homeless hostels, drug and alcohol agencies and the criminal justice system. They constitute a more or less disproportionate part of the caseloads of health, social care or criminal justice professionals. Many of them are vulnerable, deprived and often labelled as "revolving door" clients..." (Keene, 2001, p4).*

2.26. Similarly the Riddell Committee (Scottish Executive, 1999) examined special educational needs while it sought to avoid categorising children in relation to their disabilities. The Committee saw the need to define and recognise the needs of children with "severe low incidence disabilities" as a subset of children with special educational needs, in order to target services better. These were children and young people with "pronounced, specific or complex special educational needs which are such as require continuing review". Further:

> *"The degree of inter-agency co-operation, planning and support required to meet their needs is greater than that usually required to meet the needs of children and young persons. In addition, they require a high level of educational support in one or more of the following areas:*
>
> - *The physical environment*
> - *The curriculum*
> - *The degree of adult support and supervision required*
> - *The level of specialist resources, including Information and Communications Technology, required."*

2.27. The emphasis on multiple and complex needs is increasingly associated with policy emphases on 'personalisation', preventative strategies and cross-boundary working

(Leadbeater, 2004). Additionally, the notion of a continuum of need is reflected in the promotion of 'tiered' services that have the capacity to prioritise and target higher (more complex) levels of need.

2.28. The vision of the role of social work in the future is perceived as adopting a "personalized approach in helping those with most complex needs gain control of their lives and find acceptable solutions to their problems" (Scottish Executive, 2006b). While emphasising the importance of investing in prevention and earlier intervention, the social worker's role is presented in terms of this tiered approach, and it is argued that social workers should "work directly with people, alongside their families and carers where there are complex, unpredictable, longer term needs and risks" (p 31).

2.29. In line with a model developed by the Health Advisory Service (1996), Christian and McGilvary, (1999) describe services to young people with drug and alcohol problems in terms of tiers ranging from tier 1 basic generic services up to tier 4 for the minority who have particularly complex needs and including specialist services such as inpatient detoxification, residential rehabilitation for those with co-morbid disorders and adolescents in secure provision. The 'Mind the Gaps' Report (SACDM and SACAM 2003) adopts a comparable approach, with a focus on those at the extreme end of need or "people with deep seated and multiple problems which often have complex and multiple causes". Their main focus is people who experience co-occurring substance misuse and mental health problems and who also experience other complex social problems such as unemployment and homelessness.

The wide spectrum of multiple and complex need

2.30. A key challenge for this review is that it addresses a very wide spectrum of particular needs and interest groups and therefore a highly diverse body of literature. Within its limitations the review will take account of service responses to the needs of the following groups with multiple and complex needs:

- People with disabilities and community care needs in general, including older people; children and young people; people with learning disabilities; people with mental health problems; people misusing substances and who have health-related problems; and people connected with the criminal justice system
- Gender and sexuality related needs, including those of women affected by gendered violence, and lesbian and gay people
- Minority ethnic-related needs, including those of asylum seekers and refugees and gypsy travellers
- People affected by other aspects of exclusion, such as homeless people; people leaving institutions – hospitals, hostels and offenders establishments; people in rural areas, or in poverty and deprived communities.

2.31. These issues are addressed within a Social Exclusion Unit report that points out that while there are many groups with complex needs, there are 3 main broad and overlapping groups of people for whom policies consistently seem less effective.

- People with physical or mental health problems
- Those who lack skills or qualifications, both formal qualifications and broader basic and life skills

- People from some ethnic minority groups, including asylum seekers and refugees (Social Exclusion Unit, 2004a, p7).

2.32.   Subsequently in its 2005 reports, the Social Exclusion Unit further emphasises the links between poverty, multiple disadvantage and multiple needs.

THE PREVALENCE OF MULTIPLE NEEDS

2.33.   The extent to which services have to respond to multiple needs is inevitably influenced by the prevalence of multiple needs amongst existing or potential clients or service users. As noted above, there is a lack of consensus of definition and understanding of what is meant by 'multiple and complex needs', which makes quantifying the prevalence of multiple and complex needs difficult. While few studies have focused on the prevalence of multiple and complex needs specifically, there are a number of indicators in relation to the broad spectrum of needs mentioned above covered in the literature on multiple and complex needs, and this will now be discussed.

2.34.   As noted, the literature on multiple and/or complex needs, has a focus on particular client groups. Correspondently, reference to prevalence rates also tends to consider particular client groups, for example: people with psychological and mental problems (Keene, 2001), people with substance misuse and mental health problems (SACDM and SACAM, 2003), women who have experienced domestic violence (Baron, 2005; Humphreys, 2005), homeless people (Homeless Link, 2002a and b), people with learning disabilities (Scottish Executive, 2000; McGrother et al, 2001; Ridley, 2004), older people with long term conditions (Department of Health, 2006a), young people (Social Exclusion Unit, 2005b), people with particular needs regarding communication (Social Exclusion Unit, 2005a and b) and people with challenging behaviour (Hogg, 2001; McGrother et al, 2001). Information on prevalence rates as quoted in these studies is shown in Appendix 2. Further information on clients who make heavy use of services can be found in Keene (2001) Chapter one.

2.35.   Notwithstanding the attempts made in some studies to quantify the proportions of people with one or more conditions requiring service intervention, a key finding from the literature review is that there is no clear picture, at either service or strategic planning level, of service users' contacts with different services. It has been argued that this lack of information mitigates against effective planning and responses by services (for example Keene, 2001; Rankin & Regan, 2004).

2.36.   In a study of shared populations in an English county, anonymised use of health and social care services was mapped over a 3 year period. This tracking exercise concluded that 22 percent of service users were in touch with at least 2 service clusters (a cluster was defined as different delivery agencies that comprise one branch of social services, such as learning disability cluster or mental health cluster). It also found, for example, that 41 percent of social services clients with substance misuse problems also attended mental health services, indicating that these were clients with 'dual diagnosis' (Keene, 2001; Keene & Li, 2005).

2.37.   Rankin and Regan (2004) have thus argued that there should be a statutory duty on the NHS and social service departments to collect data on people who use more than one type of health and social care service. Keene and Li (2005) point out that such information would be useful for the purposes of research planning and service development, but not for individual casework or clinical purposes.

SUMMARY

2.38. A notable lack of consensus was found on the key terms used in this literature review, with terms such as 'complex needs', 'multiple needs', 'high support needs' etc often being used interchangeably. Broad definitions arguably erode the meaning and usefulness of such terms. Some authors have drawn attention to how overuse of terms such as 'quality of life' render them meaningless. Wolfensberger (1994) for example, asserts that 'quality of life' "drips with surplus meaning", and that the current eclecticism causes more confusion than illumination. Wolfensberger concludes that a concept used in such different ways by researchers, policy makers and practitioners to mean whatever one chooses, is a "hopeless term" and one that lacks scientific credibility.

2.39. Recent literature reviews and other documents provide a clear definition of 'multiple and complex needs' as referring to the most excluded people, those at the extreme end of a continuum of need. This literature review however is not intended only to focus on the extreme end of need, as this would run the risk of not addressing issues of community-based prevention and inclusion, as discussed by Rankin and Regan (2004). For the purpose of this review the terms 'multiple' and 'complex' will be considered to represent both breadth and depth of need, and the following chapters will examine literature that covers the general and particular needs of a wide range of client groups in this light.

KEY POINTS – CHAPTER TWO

- There is no consensus of definition of multiple and complex needs in the literature and the terms are applied variously

- It is often assumed that 'complex needs' is a 'given', or is commonly understood. Many authors use terms such as complex needs and multiple needs without defining them

- While the use of the terms 'complex' and 'multiple' separately have been used to describe a broad canvass of need, the terms singly and combined are also used to describe the 'extreme end' of a continuum of need

- The varied ways in which studies conceptualise and apply the terminology of multiple and complex need reflects the aims and values of researchers and policy makers.

- When these terms are used to highlight intense and interconnected needs associated with particular conditions, this can be seen to reflect the medical model and individualised treatment strategies and approaches to meeting gaps.

- When used in the sense of multiple and interconnected forms of disadvantage, this is in tune with the social model focused on inclusion/exclusion, striving to assess the ways in which structures and systems fail to meet need, and what institutional and organisational and strategic changes are required to meet gaps.

- When used to indicate degrees of intensity, complexity and interconnecting of need, the terms are used to indicate a framework for policy prioritisation and for guiding service strategies and resource allocation. How the terminology is used therefore has implications for how we see the gaps in services, what needs to happen and best practice.

CHAPTER THREE: AWARENESS OF AND ACCESS TO SERVICES

INTRODUCTION

3.1.   Two key objectives of the literature review were to explore awareness of services and options and the influences on access to services for people with multiple and/or complex needs. This chapter presents some key issues identified from the literature in relation to the constraints on awareness and the barriers to accessing a range of services including social care, health, housing, legal services, transport and so on. While the focus is mainly on the literature that specifically refers to multiple and/or complex needs, it is recognised that many of the same issues apply to all service users.

CONSTRAINTS ON AWARENESS

3.2.   The first hurdle for anyone accessing services of whatever kind is to gain information about what services are available, what these can offer, and how to access them. The wider literature on health and social care is replete with reference to problems of inaccessible information, poorly advertised services, and low awareness among potential service users of what services can offer. There is also now a considerable literature identifying aspects of best practice in relation to improving awareness (Communities Scotland: HomePoint, 2000, 2004).

3.3.   The literature on multiple and complex needs identifies various constraints that reflect individual characteristics and dispositional factors, situational as well as organisational factors, such as the complexity of service systems and inappropriateness of information and advice provision to diverse populations.

Low awareness of services

3.4.   A lack of awareness of what services are available is often compounded by difficulties experienced in obtaining appropriate and accessible information about existing services. For instance the Scottish Executive (2006b) in its review of Social Work notes that difficulties in getting reliable information about such services have been a consistent message from research. A survey by Mori in 2005 quoted in this review showed that most people have limited knowledge of what Social Work services can offer and this can result in either "unrealistic expectations" or in people not accessing services that they need.

3.5.   In respect of independent advice, the Department for Constitutional Affairs (2006) argue that while 'vulnerable people' are least likely to resolve problems and disputes, they are often unaware of where to go for advice or seek it from the wrong provider. This they say is the result of poor publicity and signposting by and of services, and because services tend to help people deal with only one problem out of the range they may have.

3.6.   Research has found that service users with substance misuse problems often lack awareness of the range of services available (both specialist and mainstream) and feel that they do not receive sufficient information about services (SACAM/DM, 2003). The problem is further magnified for those from black and minority ethnic (BME) communities as shown in a recent study of Glasgow's youth addiction services (Ridley et al, 2005).

3.7.   Stalker et al (2006) found recurring themes in relation to black and ethnic minority (BME) disabled people included a lack of awareness of services, as well as poor information provision and cultural insensitivity within services. Limited research has been conducted about BME disabled people in Scotland. Further, those from BME communities often have little or no knowledge of the range of options such as direct payments as an alternative to providing community care services, with a resultant low uptake (Riddell et al, 2005). A comparative study of older people from majority and minority ethnic groups (Bowes and Macdonald, 2000) highlighted a lack of knowledge of services, especially services available to offer help and support at home, and particularly among Asian older people.

3.8.   Although there has been limited research on gypsy travellers, studies suggest there is similarly low cultural awareness on the part of agencies and low awareness of service entitlements amongst travellers (Morris and Clements, 2001; Scottish Parliament Information Centre, 2000).

> **Good practice point**
> Studies highlight a need for more outreach work to raise awareness of services among BME communities and for increasing the profile of relevant services among professionals such as GPs.

3.9.   Keene (2001) found that some service users with complex needs did indeed lack knowledge of services, but for others this was not the case. Many were aware of the range of services, some of which they may have used over time, even if such services did not meet their needs.

Lost in translation

3.10.   Finding out what services are available can be compounded by a range of factors such as low literacy levels, language other than English as a first language, cultural factors and distance from information centres, and a lack of willingness to recognise or address problems (Terrence Higgins Trust, 2001; Ross et al, 2004; Social Exclusion Unit, 2005a; Hodes, 2005).

> *"People with basic skills and ESOL[1] needs don't respond too well to leaflets, adverts and other written information."* (Social Exclusion Unit, 2005a, p54)

> **Good practice point**
> The prevalence of literacy problems in many disadvantaged areas has practical implications for how agencies can and should communicate best. A range of approaches will be needed including those not based on written text, e.g. communicating information about services via local radio programmes.

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[1] ESOL refers to English for Speakers of other Languages.

3.11.   When English is not the first language, many people find accessing information about services even more problematic. As a result, many migrants and asylum seekers are unaware of their entitlement to health and social care services or of how to access them (Terence Higgins Trust, 2001).

3.12.   A review was conducted of users' experiences and views on interpretation and translation services in Scotland for the Scottish Consumer Council. This highlighted the under-use of interpreting and translation services and low levels of knowledge about how these services could be accessed and funded amongst public services. Moreover, it noted a low awareness of these services amongst black and minority ethnic groups (Nicholson and Wallace 2005).

"A lack of publicity by public sector organisations on the availability of translation and interpretation services contributed to confusion over how to access such help and who would pay for it".

3.13.   Additionally, this review identified a lack of consistent quality standards in interpreting and translation services and highlighted various shortfalls, including:

- Sometimes the actual meaning is lost in translation, although the document may read well. Where word for word translations are used this does not recognise the different meanings that a word may have in particular languages
- Some translations use a lot of unnecessary wording or they are presented poorly compared with original documents
- Translators who have lived in the UK for a long time may not be familiar with current institutions or everyday jargon in their home countries, indicating that recent émigrés and specialists (in areas such as health or court work) may make for the best translators and interpreters (Nicholson and Wallace, 2005).

Good practice point
The Scottish Consumer Council research (Nicholson and Wallace, 2005) concludes that there is a need to develop and implement a co-ordinated national strategy on translation and interpreting that promotes clarity about service users' entitlement to these services.

3.14.   While cross-cultural issues of interpretation and translation may be considerable for those whose first language is not English, information about services may get lost for other groups too. Parallels can be drawn in regard to the need to promote awareness of and access to services for other groups with multiple and complex needs, such as people with dementia, people with sensory impairments, and people with multiple and profound intellectual disabilities.

Good practice point
It is important to remove communication barriers (such as lack of staff time to relate to individuals), and to pursue creative and skilled communication methods including alternative or preferred formats for people with sight loss, and using visual techniques as well as words (Allen, 2001; Clare and Cox, 2003; FSIC Research Team, 2005).

Fragmented advice

3.15.   Information and advice can be fragmented, uncoordinated and problematic to access (Scottish Executive 2004c). Key problems identified by the Department for Constitutional Affairs (DCA) in its review of the Legal Aid system (DCA, 2005) were that current advice services tend to treat problems in isolation; advice is hard to access (particularly for vulnerable people); and referral mechanisms are often inefficient. Additionally, government websites are frequently hard to reach and difficult to understand. The DCA drew attention to the fact that unresolved disputes have "serious knock on costs to public services" such as Health, Police and the Department of Work and Pensions (DWP) which should be acknowledged.

> **Good practice point - Legal Services**
> There is a need for a better co-ordinated approach that ensures advice is 'people-focused'; that deals with the range of problems an individual faces; that the advice given is 'right first time'; and that the advice-giving process enables learning from mistakes, such as where services have failed to deliver (DCA, 2005).
>
> The DCA strategy aims for partnership working between the Legal Service Commission and local authorities, prioritising areas of high deprivation to develop co-located independent advice centres, with a remit to deal with the full range of problems that people present. Handover arrangements should be co-ordinated between different types of services, such as telephone advice lines involved in first point contact and specialist providers of legal advice.   Monitoring of advice presentations should inform local public service performance.

Navigating complex service systems

3.16.   Many people, including those with multiple and/or complex needs and carers, find navigating through service systems complex and frustrating. As a result they are unaware of what services there are and how these could help them. Not knowing what services were available was identified by Hardy et al (1999) as a key factor affecting informed choice for older people with complex needs, and Jarvis et al (2005) in a study on disabled children's access to housing comment:

> *"A major problem for many families is finding their way through to the kinds*
> *of help that may be available." (p27)*

3.17.   A key point stressed in the literature, is the need to recognize that current and potential users of care services have a diverse range of information needs. Additionally, guides for commissioners and other good practice documents in recent years demonstrate the importance Scottish Ministers attach to the provision of independent advocacy to enable vulnerable people to have access to representation of their needs, views and wishes (Scottish Executive, 2001a).

> **Good practice point**
> Providing clear, relevant information, advice and advocacy is essential, as has been highlighted by Margiotta et al (2003) in relation to older people. The importance of independent advocacy support to ensure disabled and other people's views and voices are heard is increasingly underlined in the literature (Ward, 1998; Scottish Executive, 2001a).

BARRIERS TO ACCESS

3.18.   Lack of awareness or knowledge of services is only one factor limiting people's access to services and support. The United Nations identify the lack of access to services as a factor that influences 'absolute poverty', defining this as:

> *"A condition characterised by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on income but also on access to services". (United Nations, 1995, p57 quoted in Gordon et al, 2000, p9)*

3.19.   While poverty generates support needs, the literature overall illustrates that a range of dispositional, situational and organisational factors may interconnect and overlap in affecting people's access to services.

Factors influencing access

3.20.   People engage with services for different reasons and in its report "Improving Services, Improving Lives", the Social Exclusion Unit (2005a, p36) identifies 3 arrangements which influence access for people with multiple and complex needs. These are:

- 'Discretionary' services, where engagement is voluntary, and these include preventative health and support services and adult education
- 'Essential' services needed by people, such as social housing when homeless, or residential or nursing care to meet changing care needs, or hospital services after an accident, and job centres when seeking work
- Compulsory services, such as mental health services under compulsory orders, Criminal Justice Services and Social Work Services, such as when children are 'looked after' or subject to protection orders.

3.21.   While these different routes and forms of access were clearly evident in the literature covered, no distinctive implications emerged in this review regarding the experience of people with multiple and complex needs in respect of these 3 forms of engagement. This might be worth considering however as a theme for subsequent research.

3.22.   However some notable patterns did emerge in respect of the constraints on access at a more general level. Key situational constraints relate to the dimensions of poverty, inequalities and location and how these impact on access opportunities. Firstly, poorer households and communities who are multiply disadvantaged are most significantly

dependant on access to the full range of public services and welfare benefits to improve opportunities and sustainable solutions (Hirsch, 2004; Somerville and Sprigings, 2005). They therefore bear the brunt of the consequences of complex, deficient and inappropriate services.

3.23.   Inequalities stemming from social class, geography, gender and ethnicity have been found to be endemic within health services (Acheson, 1998). Emerson (2004) drew attention to the impact of poverty on the health and well-being of people with intellectual disabilities and their families, and particularly to the negative impact this has on accessing effective health services. Variations in accessing health services generally are acknowledged in a Department of Health White Paper (2006a), especially in relation to responding to the needs of people from BME communities and in areas of deprivation. People in rural areas face access problems due to the location of many services, inadequate transport systems, confidentiality issues and a general lack of specialist services in rural areas (Pugh, 2003).

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Disabled people

Disabled people in general experience access problems that are well documented in the literature, for example, in terms of limited choice in housing and support as well as transport. A key constraint is the lack of physically accessible accommodation in the private sector and the high cost of physical adaptations. As a result people with physical disabilities are twice as likely as others to live in the social rented sector (Milner, 2005).

A recent literature review of services and support for young disabled people in Scotland (Stalker et al, 2006) identified barriers such as staff attitudes, the nature of the built environment, poor information provision and failure to use available technologies. The authors identified various structural and institutional barriers to accessing equal opportunities in education and to individuals achieving their full potential, although they also note improvements in some areas, albeit this is slow and patchy across Scotland.

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3.24.   As indicated above, other barriers may relate to ethnicity, gender and disability. In terms of gender, the majority of lone parents are female, who like low-income households generally, are most significantly dependent on benefits and on access to social housing. Homeless and vulnerable female lone parents are increasingly younger and many have experienced domestic violence (Smith et al, 2001; Smith, 2004). Recent research highlights that women who have experienced violence/ abuse often have multiple needs.

3.25.   An increasing body of literature emphasises the particular difficulties experienced by those from black and minority ethnic (BME) communities, whether or not they have multiple and complex needs. Lack of knowledge and a view that what is on offer does not suit people's own perception of their needs were major factors limiting access to services for older people from BME communities (Bowes and Macdonald, 2000). Additionally, BME groups face barriers to accessing housing and community care services, as well as education and work opportunities (Harrison, 2004; Milner, 2005).

Refugees

Access problems are exacerbated for refugees generally, due to poverty and multiple deprivation (Oxfam and Refugee Council, 2002), as well as for refugee children (Dennis 2002) and disabled people in refugee and asylum seeking communities (Roberts and Harris 2002). A Joseph Rowntree Foundation study (Roberts and Harris, 2002) found a lack of awareness of entitlement to community care assessment and benefits was common.

Access problems are compounded by very complex entitlements that depend on status as a refugee or someone with exceptional leave to remain, or as an asylum seeker. In the case of asylum seekers, entitlements to support in relation to impairment or health related needs have been lessened by recent legislation. For those who have personal care needs, sometimes resulting from brain injuries, the impact of being in a strange country with language difficulties, and the experience of dispersal, means that there is huge dependence on good quality information and advice about entitlements as well as support and often advocacy to access required services (Roberts and Harris, 2002; Roshan, 2006).

3.26. One Somali woman with a disability commented on her own situation:

"I do not ask for any services, I would like to, but I don't know what to request or how to initiate a request. I do not know who the service providing agencies are. I'm disabled and sitting at home" (Roberts & Harris 2002, p3).

3.27. As most workers in this field have little knowledge of community care assessments, they do not always advocate or signpost services that well. George (2000c) suggested that some refugees and asylum seekers will "feel uneasy" about contacting services.

3.28. Disabled people from refugee and asylum seeking communities do not access community care or housing services they need for a variety of reasons (Roberts and Harris, 2002). A key problem is communication: for instance, those who were deaf did not know British Sign Language prior to arrival and there are few training courses for people learning BSL through other sign languages. Support for people experiencing language difficulties as result of brain damage were also lacking. The combination of disabling barriers and lack of social networks for disabled people in these communities resulted in extreme isolation.

Gypsy travellers

Gypsy travellers historically have had uneven access to appropriate local authority sites, while their preference for using these has increased over time, reflecting a changing pattern of travelling. In some rural areas, the sites are at a distance from centres and not easily accessible. Additionally, the Communities Scotland Regulation Study (2002) found that travellers are not given good information on how to access services or on their entitlements, for example in regard to repairs standards (Communities Scotland, 2002, Lomax et al, 2000).

Low aspirations

3.29.   Low aspirations and expectations can act as barriers to services for people with multiple and/or complex needs.   Such low expectations may stem from individuals life experiences and disadvantaged circumstances, or they may reflect that significant others (including family and professionals supporting them) have low expectations of individuals or particular social groups, which in turn constrains their life opportunities and access to support.

3.30.   Recent policy addresses the issue of low confidence and self esteem or 'personal capacity' as affecting access to services.   The Social Exclusion Unit identified 'personal capacity' as an issue both preventing access to services and as having an impact on service experiences (SEU, 2005a).   One in 10 service providers responding to the SEU consultation identified lack of confidence as a barrier to accessing and using services, and this was more widespread in relation to BME communities and disadvantaged communities with low levels of literacy.

3.31.   A study by Burchaldt (2005) found that while 'young people with complex health and support needs' had similar aspirations to other young people, that is, to live independently when they felt ready, to socialize with their friends, and to do something useful, such young people were at high risk of being restricted by low aspirations.   Three groups in particular were at risk: young people with mental health problems; those with more severe impairments or more complex needs; and those who became disabled later on.

3.32.   The literature highlights that the extent to which service users are treated with dignity and respect by front line and other staff is important in determining whether they decide to use a particular service.   People with multiple and complex needs are more likely than others to report that services stigmatise and discriminate against them.   For example, people with mental health problems report stigma and discrimination in health services, while some disabled people feel that they have been refused medical treatment because of their impairment (Social Exclusion Unit, 2005a; Stalker, 2006).

Inflexible access criteria

3.33.   Organisational factors can have a strong impact on how easy or otherwise it is for individuals with multiple and complex needs to access services.   Individuals may be excluded from services because of the criteria applied for service use.   This can occur in a number of ways including applying strict age limits for accessing services resulting for example, in individuals falling between child and adult mental health services and young people in their 20s being ineligible for particular training programmes aimed at younger people (Social Exclusion Unit 2005b).   Diagnosis or more than one diagnosis required for service access can result in broader needs going unmet (Scottish Executive, 2006c; Pratt et al, 2006). Appointments and opening hours can also inhibit engagement with services (Audit Commission, 2002; Scottish Executive, 2006c).

3.34.   Service users often highlight the importance of ease and flexibility of access.

> *"I started my dialysis at Heartlands Hospital in Birmingham, but it took 30–*
> *45 minutes to get there by car. Now that I go to Ashfurlong it only takes me*
> *15 minutes. Gemma is also now able to do a full day at work because the unit*

*stays open later and she has her dialysis at 5pm". (*Source: DOH, 2006, p.151).

3.35.   Humphreys et al (2005) in an international literature review outlining the extent of overlap between substance use and domestic violence, argues that due to a pervasive 'silo' mentality (whereby agencies and professionals are trapped within discrete frames of reference), individuals' needs are not being met. For example, despite the overlap of needs, few perpetrators programmes or services for survivors of domestic abuse address substance abuse in any systematic way. Just as scarce are drug or alcohol services that explore issues of domestic abuse for either perpetrators or survivors. In the process of referral or help-seeking one or the other issue becomes lost.

3.36.   Noel et al's (2005) research into complex health care needs or co-morbidity (defined as patients having 2 or more chronic illnesses) concludes that although most of the problems are not unique to patients with co-morbidity, this magnifies and increases the probability that such problems will occur. Similarly, research by Simons and Russell (2003) found that people with a combination of mental health and learning disabilities find it problematic to access the full range of effective services they need. This was particularly true for those said to be 'on the edge' of eligibility criteria for the 2 key sets of specialist services.

3.37.   Whilst referrals were accepted by services, commonly there were disputes regarding respective services' roles and responsibilities, as well as problems with access to long-term placements. Joint service developments were said to be rare. As a result, a minority were placed out of area at some expense usually, while some requiring inpatient care either could not access such care or experienced long periods in inpatient care as there was nothing else suitable. Hardy et al (1999) make a similar point about the impact of resource decisions on accessing appropriate services.

Good practice point
Research by Abbott et al (2005a,b) and Townsley et al (2004) into the circumstances of families with disabled children with complex needs, suggests that multi-agency working improves families' ability to manage children's complex health care at home and helps them to access community schools and education.

The availability of such support is clearly a prerequisite to ensuring children who are 'trapped' in hospital, despite national policy initiatives to enable care at home and extension of education to include all children, can access the community support they and their families need (Stalker et al, 2003).

Service targets

3.38.   Increasingly, public services are subject to targets designed to measure service outputs and these may have detrimental impact on service willingness to work with clients with multiple and/or complex needs. This is increasingly being recognised in government reports focusing on disadvantaged groups (see for example Social Exclusion Unit reports, 2005a and 2005b):

> *"Targets that are primarily designed to drive up average performance of public services, or to ensure that more people achieve a specific objective, may provide weak incentives for providers to help disadvantaged people. Put simply, providers may focus on those people for whom it is easiest to get a positive result" (Social Exclusion Unit 2005 a, p16).*

3.39.   Additionally, differing service priorities and targets can inhibit joint working as services are reluctant to work outside their own area of responsibility (Social Exclusion Unit, 2005a).

Referrals

3.40.   The literature highlights a number of issues in relation to the ways in which referrals may act as a barrier to accessing services. These include a lack of referrals between agencies, illustrating not only that service users are unaware of relevant services, but so too are the professionals who might be expected to signpost them. In the absence of up-to-date service directories, professionals often rely on historic knowledge, which can be inaccurate or out of date (Scottish Executive, 2006c).

3.41.   Secondly, individuals are often given little support to access services they are referred to, leading to many failing to make contact (Social Exclusion Unit, 2005b). Thirdly, referrals may be inappropriate. For example, research has found that up to 28 per cent of mental health referrals from primary care to specialist services are inappropriate (Social Exclusion Unit, 2004b).

Waiting lists

3.42.   Long waiting lists for services have been identified as a major barrier for those likely to have multiple and/or complex needs (for example, Prewett, 2000; Audit Commission, 2002b; SACDM and SACAM, 2003; Noel et al, 2005; Scottish Executive, 2006). Often people with multiple and/or complex needs including those with substance misuse issues and other problems, require prompt access to services, and this is inconsistent with rigid appointments systems (Scottish Executive, 2003).

3.43.   Not having clear points of contact, experiencing long waiting times and the lack of rapid response were all mentioned as problematic by Onyett (2003) reviewing the development of team working in mental health. Not surprisingly, in the face of long waiting times for some services, people lose the motivation to address problems (Audit Commission, 2002b; SACDM and SACAM, 2003; Mental Health Foundation, 2003).

People with drug and alcohol problems
People with substance misuse issues and other problems experience particular difficulty in accessing services due to long waiting times or inflexible appointment systems (SACDM and SACAM, 2003; Scottish Executive 2006c).

The problem of waiting times is severely problematic for people with addictions who need rehabilitation services, and can lead to a loss of confidence in services as the following quotation from the Audit Commission report (2002b) illustrates:

> *"They don't care. You're put on a list and then they'll call you up so many months later and what are you supposed to do in that time? When you want to come off drugs, it's then, not 4 or 5 months down the line"* (Male, heroin user, aged 40).

3.44.   Prewett (2000) examining short breaks/respite care for 'children with complex or demanding needs' found long waiting lists and poor access to short breaks services for the families of such children. This arose because of a lack of suitable short breaks carers with the right training and background willing to work with children with additional needs. Requirements for accessible accommodation and/or specialist equipment and the requirement for 2 carers in some cases were also barriers.

Limited service options

3.45.   People with multiple and/or complex needs often experience inordinate difficulty accessing any services. Not only do they sometimes not know what services and support are available and how to access them, in some cases, there are no appropriate services to meet their particular needs or to ensure they exercise their right to a full life. Either they receive no services at all or the services they do receive are limited. Such problems are very relevant to the experience of children with additional educational support needs (Scottish Executive 2005a, b, d), and are also evidenced starkly in the literature in regard to people from BME communities with additional support needs. The Disability Rights Commission/CERES (2004) concluded that most services in the UK were not ready to "take on board the complex needs of disabled people from BME communities".

3.46.   Emerson's (1999) research found that people with more severe disabilities received less support from residential care staff; they had less choice; fewer chances of employment; they were less socially integrated; had a less active lifestyle; had reduced participation in community based activities; and had increased chances of being clinically overweight. Those with intellectual disabilities from South Asian communities were at an even greater disadvantage. Also, young black men with intellectual disabilities were at increased risk of placement in residential care rather than being supported in the community.

3.47.   For a variety of reasons therefore, people do not gain access to the services they need or finish up in inappropriate services.

Asperger Syndrome
George (2000b) highlighted problems experienced by a teenager with Asperger Syndrome and his family who needed a specialist residential placement but whose behaviour meant he could be dangerous to himself and others if placed in the wrong setting. Because no suitable placement could be found, there was "no option" but to place him in a residential unit that did not meet his needs and where his behaviour deteriorated.

3.48.   Research shows that children with complex needs have difficulty accessing education despite policies widening access to all children (Townsley & Robinson, 2000; Noyes, 1999). While short break provision is generally recognised as an important aspect of coping strategies for families of an individual with 'profound and complex needs', a local needs assessment in one NHS Board area in Scotland (Ridley Associates, 2004) found this type of support to be rare, and what there is tends to lack flexibility.

> **Good practice point**
> In research with practitioners working with young people with complex needs, Worrall-Davies et al, (2004) concluded that "children and young people with complex needs" should access services earlier.

3.49.   Recent studies show huge inequities in accessing the option of direct payments across the UK, with England having around twice as many direct payment users relative to its population compared to Scotland, Northern Ireland and Wales and despite having a lower proportion of people with long-term illness or disability (Riddell et al, 2005). People with physical and sensory impairments remain the most common recipients and people with mental health issues, including dementia, the least likely to access Direct Payments. Another issue is that these payments have been used mainly to support personal care, which means their potential to advance social justice agendas as envisaged remain to be realized (Witcher et al, 2000).

KEY POINTS – CHAPTER THREE

Awareness

- The general literature is replete with references to problems with a lack of or inaccessible information, poorly advertised services and low awareness of what services can offer
- People from black and minority ethnic communities, refugee and asylum seekers have particular difficulties in accessing information and advice about services
- There are particular shortfalls in interpretation and translation service and a lack of awareness among individuals and agencies about how to access such services
- Many people, including people with multiple and complex needs and their carers, are daunted by complex service systems
- It is increasingly recognised as a principle of good practice that it is important to provide clear, relevant information and advice about services
- A range of approaches are needed to meet the diverse communication needs of current and potential service users
- Independent advocacy is important in ensuring that people with multiple and complex needs have access to representation of their needs, views and wishes.

Accessing services

- Accessing the 'right' services is made more problematic by dispositional and situational factors such as sexual orientation, being an asylum seeker, a drug user, or having mental health problems and other issues
- Poverty and inequality are structural factors that impact on disadvantage in accessing services. Low aspirations have an impact on the opportunities available to people with multiple and complex needs and the support to live a full life on their terms – both in terms of their own low expectations and those of others
- Certain groups, such as disabled people, generally experience a number of access issues or barriers (physical and intellectual)
- People with multiple and complex needs may be excluded from services either because of the criteria governing service use (e.g. age restrictions) or that services focus on addressing a single issue
- Service targets can have detrimental impacts for service willingness to work with clients with multiple and/or complex needs
- There are a number of issues around service referral e.g. lack of referrals between agencies and inappropriate referrals
- Long waiting lists for services pose particular problems for those likely to have multiple and/or complex needs
- For a variety of reasons, many people with multiple and complex needs do not gain access to the services they need or end up in inappropriate services.

3.50. Given the focus on service pathways, the following table summarises the findings of this chapter in relation to the stage of the service pathways covered, related processes and influencing factors and implications for service responses. A similar framework will be applied at the end of Chapters Four and Five.

Table 3.1. Awareness, experience of access and service implications

Pathways stage	Processes/influencing factors	Service requirements
Options/ pre-access *Awareness*	Low awareness Service ethos and model Availability of information Accessibility of information in different formats Service approach – proactive or reactive Complexity of service systems and how communicated	Promotion and information to ensure/maximise awareness Information in different formats reflecting diversity Information link workers or brokers Accessibility Jargon free information Appropriateness Reaching out to some groups – e.g outreach with BME young people Training
Accessing Service	Individual needs & preferences Aspirations of and for people with multiple and complex needs Service ethos, culture, systems Diversity of need Transport Accessible buildings Suitability of resources Flexibility of approach Access to health services negatively affected by social inequalities, cultural differences in health beliefs and behaviours and poverty (Emerson, 2004)	Transparent referrals system and clear criteria Early support for families with children with complex needs Choice An ethos of involvement throughout the organisation Understanding of role of independent advocacy Adopting a social model of disability Suitable locations Accessible building Accessible and flexible transport Flexible opening hours Trained, experienced staff Attention to particular needs Positive, user-friendly reception Interpretation/ translation services

CHAPTER FOUR: EXPERIENCES OF SERVICES

INTRODUCTION

4.1.   Having considered issues of access to services for people with multiple and complex needs, we now focus on their experiences of pathways in and through services. The themes covered in this chapter relate to service users' experiences of care and support, the impact of transitions, the issue of what is called 'non-engagement'; patterns of participation and service outcomes.

EXPERIENCES OF CARE AND SUPPORT

4.2.   Some commentators like Rankin & Regan (2004) sound the alert that those who are most disadvantaged and who have the most complex needs have the poorest experience of services and are at greatest risk of their needs not being met - the 'inverse care law' (Tudor-Hart, 1971). While this may be true it should be recognised that people with multiple and/or complex needs are not the only groups to be disadvantaged by deficits and gaps in services. Barr et al (2001) found that users of community care services share concerns with others in the community about many aspects of public services, including transport, safety, planning, leisure opportunities, accessibility and participation. Exclusion is a "powerful common denominator between care users and others in the community" (Barr et al, 2001 p.5).

4.3.   Broadly, the quality of service users' experience and outcomes relate to the complexity of systems of provision, how these are commissioned, co-ordinated and resourced, the nature of staff practices, partnerships and joint work and user involvement and empowerment.

4.4.   The literature overall illustrates that while 20 years ago many people with multiple and complex needs were accommodated and cared for in institutional settings, policy movements in community care, criminal justice, children's services, housing and homelessness have promoted more diverse, community-centred systems of provision. One consequence is the multiplication of services and professionals involved in people's lives. For someone with both mental health and substance misuse problems relevant professions may include, for example, a social worker, a GP, a housing officer, support workers, an occupational therapist, mental health services, and/or addiction services (Petch et al, 2000, Parts 1 and 2). A similarly wide spectrum of service involvement has relevance to older people or people with a disability who have additional needs, or to people resettled from criminal justice establishments, younger people who have been in care, or homeless people or refugees who have been resettled in the community.

Assessment

4.5.   Recognising that many people identified as having multiple and complex needs may be in contact over time with several professionals, at various stages they may have to undergo a formal process of assessment. While generally, the assessment of a person's needs is pursued as a matter of good practice, it can also be required by statute or as a condition of funding, as in the case of community care, criminal justice, and Supporting People services, for example.

4.6.   Many service users and carers appear not to be familiar with either their entitlements to assessment, or with its role in the support planning process (Scottish Executive, 2001b, 2002a). This low awareness is potentially disempowering as assessment has a gate-keeping function. As the Guidance itself identifies, "assessment is not an end in itself. It is a necessary means of accessing support and services" (Scottish Executive, 2002a).

4.7.   People may feel daunted by the assessment process, because they are concerned about its outcomes, or they experience it as intrusive, or they are traumatised. Initial assessments by whichever agency are therefore often unlikely to identify issues relevant to multiple and complex needs, which imply 'breadth and depth of need' (Rankin & Regan, 2004). It has been pointed out that "psychological and social problems may not be presenting problems" (Keene 2001, p.4), and that "the most vulnerable service users may be the least able or willing to articulate their needs and the least confident in accessing services" (Edwards, 2003). However, repeated presentations or referrals and contact over time, may allow the trust that is needed to enable a deeper assessment to be developed.

4.8.   At times the professionals conducting assessments may lack awareness of particular configurations of multiple and/or complex needs, or may not understand their import and impact. Such low professional awareness risks inappropriate assessments and emphasises the need for staff training and cross-boundary working, which will be discussed in Chapter Six.

Complex needs and complex assessments
AIDS-related neurological and psychiatric disorders can be confused with Alzheimer's, and the pneumonia commonly associated with HIV (PCP) is sometimes mistaken for lung disease and heart failure (Age Concern/ Institute of Gerontology Report "Breaking the Silence", quoted in Community Care (George 2000d).

Beyond difficulties with medical diagnosis, alcohol related brain damage (ARBD) can be hard to distinguish from other causes of brain damage such as head injury or early onset dementia[2]. As those affected are a diverse group, who may live in the community or in inappropriate health or social care facilities, ARBD is often 'an invisible condition' that may persist until a crisis occurs (Cox et al, 2004). Cox et al further suggest that a person's needs may be categorised and packaged in a way that makes sense to service systems, but not to the individual or those who support them.

4.9.   A further issue relates to the role that stigma can play, on the one hand in inhibiting people's willingness to discuss their needs with professionals and on the other in the approach and response of the professionals conducting assessments.

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[2] In "A Fuller Life" (Cox et al, 2004d) defines dementia as a variety of illnesses and conditions which result in a global impairment of brain functions and a decline in intellectual functioning, personality changes and behaviour problems.

> **Older people with additional needs – impact of stigma and insensitivity**
> Age Concern alerts us to the plight of older people who are lesbian or gay and who are confronted by illness or disability (Manthorpe & Price, 2003), or by needing to go into care. Such older people may not communicate their sexuality because they fear prejudice amongst staff and other service users (Sale, 2002).
>
> *"Overwhelmed by fear and the risk of stigma, so they were often isolated emotionally with little personal support. And even if their peer group knew about their condition, they didn't know how to offer support. Few approached social care professionals, or asked for services because they thought others were more deserving. This makes it difficult for social services departments to provide effective and appropriate services unless efforts are made to reach out to people who feel unable or unwilling to seek help"* (Age Concern, 2002).

4.10.   Other problems identified with assessments included:

- Though the case for sensitive, participative and comprehensive assessments is stressed in the literature, the reported experiences of people with multiple and complex needs imply that such criteria are met inconsistently
- People may be at risk of 'falling through the service net' because of multiple assessments (Rankin & Regan, 2004; Keene, 2001; Bevan, 2003; Scottish Executive, 2004)
- Joint assessments are underdeveloped in response to multiple and complex needs
- The blocks and waiting times that service users face in relation to accessing or sustaining the services that they need occur at various stages (Edwards, 2003).

> **Risks of failure – substance misuse**
> People with a drug or alcohol problem who want their support to continue beyond the originally specified period, can find this may not be funded by the care manager following a care plan review. If they relapse it can be hard to access further support (Edwards, 2003).

Fragmented service responses

4.11.   A metaphor used in a Turning Points publication captures the experience of many service users:

> *"Imagine trying to get your car fixed after it breaks down and finding that you have to take it to a different garage to fix each part – one to change the brake cable, another to fix the windscreen, a third to change the tyres and so on. Even worse, each garage is in a different area and none of them share information, so you have to repeatedly explain the problem and fill out separate forms at each visit"* (quoted in Hudson et al, 2005, p.13).

4.12.   Various impacts of service fragmentation on service users' experiences have been identified.

- Professionals work "in isolation from each other" (Keene, 2001 p6; Northmore, 1999; Rankin & Regan 2004)
- Service users may be in contact with and receive services from varied agencies and staff – "it can be a very crowded market" (Edwards, 2003)
- Agencies' responses are often divergent and limited.

Substance misuse and additional issues

Someone with serious drug dependency may be treated by their GP as a medical problem, by a drug agency as needing treatment of harm reduction and by the police as a possible threat to public order. *"Little, if any, account is taken of problems presented by the same people to other agencies*" (Keene, 2001, p3).

Multiple, chronic health conditions

One American study (Noel et al, 2005) focused on caring for "patients with multi-morbidity" or multiple, chronic conditions. This identified 6 key problem areas: physical symptoms; psychological reactions; relationships; work and leisure; multiple medications; and problems in interacting with health-care providers or the health-care system. These problems were compounded by long waits for referrals, poor continuity of care between clinics, problems in accessing urgent care, multiple appointments and problems communicating with providers.

4.13.   The authors concluded that many of the above problems were not unique to people with multiple needs, as people with a single chronic illness may take more than one medication, experience side-effects, have difficulty communicating with their provider, or experience poor continuity of care. However, facing multiple issues appeared to magnify people's problems or increase their incidence. Moreover, people may get 'stuck' in using inappropriate services (Rankin & Regan, 2004; Keene, 2001; Bevan, 2000a and b, 2003).

HIV and sexuality

A Terrance Higgins Trust Report (2001) suggests that HIV agencies are often ill-equipped or unwilling to meet service users' mental health needs, while mental health agencies cannot see beyond their HIV and refer them back to HIV services. HIV services may misinterpret mental health problems as bad behaviour and simply exclude a difficult service user rather than working with local mental health services to help them.

4.14.   In terms of its cultural impact fragmentation is seen to generate a 'silo mentality' which restricts professionals' frames of reference and responses. Structurally it can cause a 'revolving door', whereby a person persistently re-presents with minor immediate needs, but underlying difficulties are never tackled (Keene, 2001).

Medical model

4.15.   Some authors stress that 'the medical model' can stigmatise and restrict people's life opportunities (Morris, 1996). Disability from this perspective is seen as a pathological physical/ medical condition that determines a person's needs. This approach is associated with an emphasis on clinical diagnosis (Rankin & Regan, 2004) and on medical and institutional responses to the support needs of people with disabilities. People's needs are not seen as a whole.

4.16.   The 'social model', in contrast, views 'the problem' in terms of the 'disabling barriers' that current social arrangements and institutions place on the living and support options for disabled people, whether in the form of "negative attitudes or physical, social or economic factors" (Morris, 2004, p.6).

4.17.   While the medical model predominated historically, the social model has increasingly gained acceptance, so generating more ordinary living options (Oliver, 1996; Oliver and Barnes, 1998; Priestly, 1999). However concerns persist about the impact of the medical model on outcomes for people with disabilities and multiple needs. Rankin and Regan (2004) point out that medical diagnosis (rather than the condition itself) is considered by many voluntary sector participants as a catalyst to social exclusion, as a purely clinical diagnosis "may make it impossible to respond to complex needs". They quote the Head of MIND's legal services:

> *"The fundamental point is that discrimination arises because of the diagnosis, not as a result of the condition itself" (Rankin & Regan, 2004, p.61).*

Dual diagnosis
4.18.   For 'dual diagnosis' clients, the medical perspective may dominate outcomes to the extent that social support needs are undermined. Outcomes may be delayed or limited, for example, if there is straightforward psychiatric intervention rather than a social model of support (Rankin & Regan, 2004).

Dual or multiple diagnosis
A study of the experience of people with physical impairments who also have mental health support needs found that "very few mental health professionals took account of medication prescribed for a physical condition when treating mental illness" (Morris, 2004 p.10). One interviewee said, "I have to go to one town for my body and another for my mind", and another reflected the views of many, saying: "I'd like to see an assessment which doesn't just do physical disability or mental health or whatever. That looks at the whole" (Morris, 2004: p 55).

Edwards (2003) uses the example of one service user who suffered from anxiety, paranoia and a lack of confidence, who was seen by a psychiatrist and a CPN for 8 years, before they gained access to the practical support they needed to tackle everyday tasks in the community. It was found that many service users felt it took a long time to get the type of services they need that might make a real difference.

One quantitative study covered 348 people with a learning disability and mental health problem who have long-term support needs, some of whom were found difficult to engage by services. Although mental health services do work with this group, the study found that inter-service disputes arise about roles and responsibilities and that there can be problems in accessing long-term placements (Simons & Russell, 2003).

Positive experiences of active outreach

4.19.   Some service users with dual needs reported very positive experiences of follow up services of for example, being listened to and followed up by outreach workers in specialist, targeted services:

> *"I would say that (this project) is probably the best thing that's happened to me in a lang time. They listen tae ye. If you've missed an appointment they will phone you up and ask us up. You get a sense that they care mair aboot ye there. Now I'm gang doon there 3 times a week to get the Reiki and acupuncture"* (Scottish Executive, 2006c: p 43).

> *"I think the co-morbidity team is the best because they get a hold o' ye and keep pursuing ye until they get ye. Some days I don't come but they're persistent tae get a hold o' ye and they go looking for ye" (*Scottish Executive, 2006 c: p43).

Limited service vision
4.20.   Even if someone's multiple needs are known to agencies, professionals may use tried approaches rather than seek creative solutions that meet people's needs (Keene, 2001; Rankin and Regan, 2004). For example, a traditional day centre service may be presented as the only option for people with a learning disability and additional mental health or addiction needs (Clark, 2001). Alternatively, we have seen that some services exclude people with multiple and complex needs for reasons of limited vision or limited resources.

4.21.   A recent study points to a serious lack of integrated effective service responses to women who have suffered domestic violence and use drugs or alcohol as a coping strategy (Humphrey et al, 2005).

'Silo' responses in regard to domestic violence
Of 60 women using crack cocaine, 40 percent reported they had been regularly physically assaulted by a current partner and 75 percent assaulted by a current or previous partner. Half had needed hospital treatment in the past year due to partner violence (Bury et al, 1999).

Despite this extreme situation, few perpetrator programmes or services for survivors address substance use systematically. Just as scarce are drug or alcohol services which respond to domestic abuse issues for either perpetrators or survivors. In the process of referral or help seeking, one or the other issues becomes lost (Humphrey et al, 2005).

A survey of Women's Aid and related refuge services found "grossly inadequate" emergency accommodation provision for women with high support needs, and that existing provision was inflexible. Refuges were often unwilling to take women without "parallel support" from other agencies. Only 8 percent of refuges said that if space was available they would admit a woman with a substance misuse problem or a mental health problem (Baron, 2005).

Inadequate and insensitive responses compound the stigma experienced by people with multiple needs. 'Non-refuge' providers may question women's credibility, be unable to provide suitable support, or be seen to threaten the loss of their children. Such responses are seen to reflect a poor appreciation of domestic violence and that services may only respond to presenting issues (Baron, 2005).

4.22.   Baron argues for a 3-pronged strategy for improving the response.

- Refuges need to be resourced better
- Some specialist refuges may be required
- Training and guidance are needed for mental health and substance misuse services to move people away from "the narrow focus on their particular specialty and respond in a holistic way to client's needs". Women's Aid has produced a series of Guidance Notes to this end.

Care management and co-ordination

4.23.   Noel et al (2005) point out that, although the impacts of fragmentation are not peculiarly experienced by people with multiple and complex needs, their consequences may be magnified. Both care management and related examples are considered in this light.

4.24.   Service users are often surprised to find that services are not co-ordinating their respective inputs or not sharing information to avoid duplication of effort. The Scottish Executive's "Modernising Government" report (2003a) quotes an old man who reflected, *"So that's why the District Nurse always seems to turn up just when the Home Help is taking me to the Day Care Centre for my carpet bowls" (p3).*

4.25.   Another service user commented:

"I just don't understand why there can't be one file that's got all the information on you and that goes from place to place…What's difficult about that?" (Scottish Executive Effective Interventions Unit, 2003)

4.26.   Formal care planning frameworks are commonly developed where intensive needs are identified, or there are legislative provisions that require this, such as pathways assessments and plans for young people in and leaving care[3], and the care programme approach for people with serious mental health problems "who also have complex health and social care needs" (Scottish Executive, 1996). Good practice requires that care planning focuses on ensuring

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[3] The Support and Assistance of Young People Leaving Care (Scotland) Regulations 2003

integrated care pathways (Scottish Executive 2003c, 2004b,d) and that service users are involved in support and care planning processes throughout (Scottish Executive, 2004a).

4.27. On the face of it, care management, which was developed in the 1970s in the U.S.A as an attempt to improve co-ordination of care and access to fragmented services, should be highly relevant for people with multiple and complex needs who depend on many services, and are at heightened risk of admittance to hospitals or other institutions. Indeed early guidance from the Social Work Inspectorate also suggested that groups with complex needs be given priority in care management.

4.28. Scottish Executive guidance (2004a) noted that care management had "lost its way" and that an earlier review found inconsistency in policy and practice in care management across Scotland (Stalker & Campbell, 2002). The review highlighted problematic responses to complex and multiple needs. Though most workers holding 'complex' cases were qualified, a quarter had not received any training in care management, and 'intensive' caseloads were considerably higher than optimal. Of particular concern was that only 16 percent of the care managers were located in multi-disciplinary teams, while only one authority had budgets devolved to care managers. A separate review found a similarly uneven implementation of care management in England (Marlowe et al, 1999).

4.29. So far it appears that care management has failed to realise its potential for a positive response to complex and multiple needs. Most recently it has been redefined by the Scottish Executive as "intensive care management" to be targeted at people with complex needs or with frequently or rapidly changing needs (Scottish Executive, 2004a). Additionally, intensive care management is seen as being aligned to single shared assessment, which is discussed later (see paras 6.39. and 6.40. and Appendix Three).

4.30. Experience since 1990 would suggest that financial control and managerial agendas have prioritised care management's administrative and gate-keeping functions at the expense of advocacy and collaboration to meet needs. Various new roles proliferate - such as community matrons (DOH, 2005a, 2006). However, it is very unlikely that these will resolve the underlying tensions. It is early days to comment on whether the Supporting People programme operates any more holistically and flexibly in its response to meeting multiple and complex needs.

Financial constraints on support planning

4.31. Care managers considered that the key factor affecting assessments and service responses was that of increasing pressures on budgets (Marlowe et al 1999). Choices about initial services or later changes in providers depended less on service users' and carers' views than on the existing budget position and whether or not 'in-house' services were available. Notably it was found that though service users find the care system complex and confusing, they largely accept the resource constraints on care managers (Marlowe et al, 1999).

Older people

Older people with the most complex needs felt pressured to enter residential care, because it was too expensive to maintain them in their own home. Additionally, budget pressures resulted in those with lower support needs (such as for cleaning and other practical support) not getting this (Hardy and Young, 1999, p488).

4.32.   Other constraints on access to key sources of funding for support for independent living have been identified. Regarding the benefits of the Supporting People programme Goldie states "many people with multiple needs have been assisted in ways that would not have been possible before" (Goldie, 2004a, p1) and "one of the biggest reported benefits of Supporting People has been to provide assistance to many people on the margins and to bring people excluded from services some limited support" (Goldie, 2004a p2). Successes of the Supporting People programme for people with multiple issues have included:

- Providing 'floating support' for people living independently
- Flexibility in staffing levels depending on levels of need.
- New legal rights for residents who become tenants
- Additional personal income for tenants
- Greater independence and responsibility for residents
- Freedom to make building and refurbishment changes.

4.33.   Overall budgetary constraints in the context of high demand have resulted in difficulties in accessing higher levels of Supporting People funding required to meet additional support needs (Goldie, 2004, a and b; Watson et al, 2003). Goldie concludes that 'Supporting People' has been "a victim of its own success" (Goldie, 2004b).

Lack of consultation and choice in care planning
4.34.   Hardy and Young's research was interested in the extent of user choice in the care management process for older people in 4 local authority areas. Only one of the 28 service users interviewed remembered being asked about her satisfaction with the proposed care package. None of those receiving home care had been given a choice of service providers. One carer said:

> *"We didn't really know anything about it. It was just a matter of they said, 'so and so will take care of this and so and so will take care of that' and at the time I was just glad of the help" (Hardy and Young, 1999, p488).*

Communication barriers limiting participation and choice
4.35.   For people with learning disabilities and 'high support needs', or 'profound and multiple needs', there is a high risk of exclusion from decision-making because of communication difficulties (such as no verbal communication) and/or challenging behaviour. This was most notable at times of transition (Beamer & Brookes, 2001).

Learning disabilities
Choices offered to people with learning disabilities and high support needs tended to relate to day-to-day rather than life-changing matters – for example, where to live, who to live with, or leaving school. They also took place at times of transitions - leaving hospital, leaving home, leaving school, major loss or illness (developing dementia).

In practice, decisions were influenced by established practice as well as by professionals' views on the client's 'best interests', on risk adversity and available resources. Rarely was the individual with high support needs at the centre unless an active parent, supporter or circle of support put him there (Beamer & Brookes, 2001).

Contested territory and poor outcomes

4.36.   Service users and/or their carers often disagree with professionals' assessments of their options (Keene, 2001).   Whereas many service users are accepting of resource constraints, in other instances disagreements arise between providers and service users if options are constrained by resources or by limited vision – for example if professionals favour residential care rather than ordinary housing and support for an older person, or a 'dry' rather than a 'wet' facility is identified for someone with alcohol problems, or a child is taken into care (Rankin & Regan, 2004).   Keene states:

> *"clients often see professional assessments as unhelpful, and professional interventions as inappropriate, restricted and time-limited.   This disparity forms the main obstacle to effective intervention" (p113).*

4.37.   Several studies found that assessment and support was problematic because the person was unable or did not want to accept help for various reasons, and both persistence and joint work were required on the part of service providers. In other instances the differing preferences of professionals and service users reflected the squeeze of limited resources.

4.38.   Another scenario, given fragmentation, is that professional assessments diverge because of different approaches.   The net effect is disjointed assessment and planning between housing, social work, health or voluntary sector services.

Children with disabilities
A Joseph Rowntree Foundation study surveyed parents of children with severe disabilities, obtaining a 60 percent response rate from around 3000 parents, many of whom experienced housing problems.

It found that housing needs were rarely taken into account in Children Act needs assessments, that only a minority had help from statutory services to address housing needs and no single department or agency was responsible for addressing needs. Three quarters had not had needs assessed by an occupational therapist. Links between mental health and learning disability services appeared to be under-developed (Beresford & Oldman, 2002).

THE CONTEXT OF TRANSITIONS

4.39.   The literature contains an abundance of examples of problematic assessment, support planning and provision in the context of transitions.   Often these delayed people gaining access to the services that they needed or limited their rights.

4.40.   The need for ongoing assessment and reviews are critical in planning person centred support, and particularly in the context of transitions. Some problematic transitions that may affect people with multiple and complex needs, include:

- The onset and development of long-term or chronic conditions, such as multiple sclerosis, HIV Aids, Huntingtons, dementia, or traumas such as brain injuries (George, 2000a; Terrance Higgins, 2001; SHA, 2006; Hudson, 2005)
- The uneven development of conditions such as autistic spectrum disorders (ASD) or Aspergers (George, 2000b)
- Age-related transitions, such as when young service users have to start using adult services; or that determine when young people have to move on from care
- The onset and development of substance misuse-related conditions, including those related to severe mental illhealth or alcohol related brain damage (Cox et al 2004; McRae & Cox, 2004; Baron, 2005)
- The sudden illness or death of a relative or carer can be at the root of intense distress that compounds existing health problems or disabilities or creates new ones. This creates risk and vulnerability to other problems and can result in crises such as homelessness (Crane, 2004)
- Leaving criminal justice establishments, hospitals or large hostels (Petch et al, 2000; Rosengard Associates with Scottish Health Feedback, 2001)
- Having to flee home or country of origin due to violence or threat of violence or abuse (broadly defined), as in the case of young unaccompanied asylum seekers and asylum seekers and refugees more generally (Hopkins and Hill, 2006; Cemlyn and Briskman, 2003, Okitikpi and Aymer, 2003; de Lima, 2005; Hodes and Tolmac, 2005). Other migrants seeking work may have left circumstances of major poverty and hardship and have language difficulties (Edgar et al, 2005).

4.41.   Positive experiences of support in the context of transitions are evident where services have been targeted to respond to particular needs (e.g. age, gender or shared circumstances) and operate in a person-centred and holistic way. Examples will be covered in Chapter Six.

Moving out

4.42.   Moving on from short or long-stay hospital services appears to be seriously problematic for those who have additional or multiple needs.

> **Children with disabilities moving from hospital to community**
> Stalker et al's (2003) key study focused on children with disabilities and serious medical conditions who were 'trapped' in hospitals in England and Scotland despite policy initiatives to enable care at home and to equalise access to education. The study covered a range of 'impairments' (physical, sensory, emotional, cognitive) although not psychiatric diagnosis. There was little knowledge gained about children from ethnic minority groups in this or other studies cited.

Planning and resource gaps

4.43.   It was found that the pattern of delayed discharge was exacerbated by the discrepancy between advances in medical care, which could speed up treatment and maintain lives better, and the inadequacies of the social and community based support on offer within the community to meet children's needs on discharge (Stalker et al, 2003). Though joint working was often ineffective between social work, education and health, for example, innovative and collaborative practice did emerge. The net effect was that children and young people often had long waits in hospital for care packages, accommodation and adaptations in the

community. The rise in those supported at home has not been matched by additional funding for community based services. (p27) Overall, parents were important advocates for children, though they had a low awareness of complaints procedures even if they had received a copy.

4.44.   Similar issues emerged in a study of adult hospital reprovisioning and resettlement in the fields of learning disability, mental health and physical disability in Scotland. (Petch et al, 2000). Both studies indicate that the problems are not about 'difficult' clients but about 'inadequate services' (Morris, quoted by Stalker et al, 2003). However although Petch et al's study found that "for the large majority the outcomes are highly positive", it highlighted the extreme difficulties faced during such transitions.

> *"Reprovisioning and resettlement programmes have a considerable emotional impact. Their planning and organisational momentum creates uncertainties and instability for the individual hospital residents who are to be resettled in the community. People often face considerable uncertainties and fears about their future lives, they have their needs assessed and re-assessed by different professionals, and they may be moved between wards and hospitals as service provision contracts at the hospital end. Timescales, resources, planning requirements and contingencies can mean individuals experience a significant level of unsettlement and disturbance as part of the process (Petch et al, 2000, p73).*

UNSETTLED PATHWAYS, FRAGILE SOLUTIONS

4.45.   Beyond the problems identified earlier in regard to navigating complex service systems, some research identifies 'revolving door' scenarios associated with particularly poor outcomes. Essentially, individuals access several different services, while none of them properly tackle multiple and complex needs.

4.46.   People defined as having 'multiple and complex needs' by the Human Service Department of Victoria, Australia, had become involved with a wide range of services "without clearly established case management and funding responsibility" (2003a, p5). Often they could access services but were referred between them as they do not easily fit their legislated or service eligibility criteria:

> *"Services may avoid acceptance of ultimate responsibility since each agency can claim that they are not mandated, funded or equipped to accept such responsibility…" (p5).*

4.47.   Again this has resonance with the UK experience where people who have substance misuse, mental ill health, offending and homelessness histories may both have accessed a number of services and experienced exclusions from services. Keene (2001) argues that many services focus on particular needs rather than on wider problems and that the lack of appropriate alternative or move on accommodation and support services then serves to compound problems and difficult behaviours for example, after being in prison.

> **The traditional 'revolving door'**
> John, a homeless man in his 40s who was involved in chronic alcohol misuse slept rough for around 7 years in urban and rural areas, interspersed with stays in direct access accommodation - "alcohol blocked the hurt".... "I became a loner, very unkempt ....like a tramp." He stayed rent-free in a 'dry house' for a year doing the catering, but had to leave after a drinking binge. Later he stayed for 8 months in another dry house, where he liked the rural setting and went fishing, but "blew it again". Another hostel stay followed until he was admitted to hospital seriously ill. He left hospital in a wheelchair and was accommodated by the local authority before going on to alcohol rehabilitation (Rosengard et al, 2002).
>
> Peter a young homeless man interviewed in a seaside town for a research project on rural homelessness, had been homeless on 8 or 9 separate occasions and was using drugs. He had left home at 16 because "me and me step-mum weren't getting on" and he had stayed in London, in Scotland and in the South of England. He slept rough in towns and rural areas and he used survival skills developed during a short period in the navy. His life-style led to several periods of imprisonment (Cloke et al, 2002).

4.48.   Other 'revolving doors' relate to unsuitable move on arrangements from institutions.

> **Revolving door following hospital resettlement**
> One study of 2 groups of people with learning disabilities and 'challenging behaviours' – 'hard-to-place' hospital residents and a group whose placements broke down – shows how resettlement arrangements can be fragile when planning and joint working are inadequate. (Sergeant et al, 2004) The study concluded that: a single model response was inadequate; support must be individually planned and flexible; high levels of support are required but are expensive in dispersed tenancies, and a partnership is required between providers, individuals and families.
>
> Petch et al's study (2000) similarly found that assessment in the institutional setting at times led to solutions that did not meet needs and were unsustainable, such as an individual rehoused into a house in a third storey of a tenement who was unable to negotiate the stairs. His disabilities had not been identified as he had stayed in a single storey hospital building.

Equivalent poor outcomes associated with revolving door scenarios were repeated in respect of different client groups with multiple and complex needs covered in this study.

NON-ENGAGEMENT, EXCLUSION AND LOW PARTICIPATION

Non-engagement

4.49.   A pattern of 'non-engagement' or 'non-compliance' with services has been considered within the literature, with some studies attributing this to individuals' multiple problems and lack of motivation, while others consider 'non-engagement' as reflecting

poorly designed, inappropriate services. Rankin and Regan stress that non-engagement is best seen as a poor service outcome attributable to inappropriate services, rather than simply to service user 'choice' (2004: p 97). They apply the 'inverse care law' to explain exclusion; in other words those with greatest needs are at greatest risk of getting the least services, largely because multiple interconnected needs are not responded to with a 'whole person' approach.

4.50.   Potential influences on non take-up or rejection of services at different stages may include the following patterns:

- Service users do not trust professionals due to prior experiences or are inhibited for personal reasons or embarrassment (Keene, 2001)
- Some service users (and carers) have very low confidence in the likelihood of gaining either useful advice on options, or positive outcomes, with low expectations often found within particularly disadvantaged communities. Additionally there are the asylum seekers/ refugees with language difficulties (Nicholson and Wallace, 2005) or who have been traumatised and/or have had experience of "a punitive regime of rigorous investigations and insecurity", as well as 'grudging services' (Pearl & Zetter, 2002)
- The culture and communication style of a service may leave people feeling uncomfortable or put off, such as when there are cultural insensitivities in communication with minority ethnic households, or when service users feel probed too deeply. (Rosengard et al forthcoming, 2006)
- Tightly structured appointment systems are not consistent with chaotic lifestyles (young people, homeless people and people with mental health issues) (Edwards, 2003, Rankin and Regan, 2004)
- At different stages people are not ready to acknowledge or address addictions or mental health issues (Keene, 2001)
- Personal crises destabilise people, so that non-compliance and sometimes serious incidents occur, resulting in further cycles of exclusion, exacerbated poor health or injuries, and disengagement or institutionalisation (Rosengard et al, 2002).

4.51.   The following example was addressed in a topical Mental Welfare Commission for Scotland Report (August 2006). It stresses the importance of strategic and co-ordinated care planning and joint working to prevent cumulative problems for people with Alcohol related brain damage (which is increasingly referred to by professionals as ARBD).

An extreme case of risks associated with Alcohol Related Brain Damage
The case of "Mr H" who had used services for over 20 years in relation to his chronic alcohol abuse and its problematic impacts, was investigated by the Mental Welfare Commssion. Mr "H" was eventually suspected as having Alcohol-related brain damage and Guardianship was granted due to dementia. His history involved multiple uses of different services, interspersed by periods of 'non-engagement', as well as behaviours that resulted in services not responding, until neighbours reported that he was starving and his house was infested. He was found to be living in human degradation.

Mr "H"'s case highlights the high risk that mental and physical health and other problems such as acquired brain injury, may be masked by alcohol misuse histories and related uncooperative behaviours. It reminds us that if professionals simply accept that people's 'non-engagement' with services is attributable to continuing alcohol abuse, then statutory responsibilities and protection may be seriously undermined.

Overall the case identified gaps in assessment, in professionals' knowledge of legal responsibilities and entitlements, in risk assessment, in staff supervision, in communication and co-ordination, in joint working, in poor recording by agencies, as well as a lack of strategy in relation to service responses in respect of Alcohol-related brain damage. The Commission's recommendations included the need for proper assessment of individual's capacity to consent to or co-operate with the proposed care and treatment; joint Health and Social Work protocols for assessment, care management and related information sharing in complex cases potentially involving Alcohol-related brain damage; that Health and Social Work should audit the assessment, care management and treatment of those who are regularly in contact with services due to alcohol dependence; and that Drug and Alcohol Action Team Corporate Action Plans should include specific reference to people with alcohol-related mental disorder.

4.52. Service users may be discouraged from engaging with a service because their wants and expectations differ from those of service providers. Keene (2001) stresses that many people with complex needs essentially want help with 'maintenance' and sustaining their current situation, including with ongoing support. Professionals on the other hand tend to prioritise change in the life of service users. While this may be true long-term for some service users, service users' self-expectations may change over time – whether following a crisis point, or a contact with an individual professional, or particular service, that they can relate to, develop confidence in, and trust to engage with.

Experience of exclusion from services
Edwards (2003) reported on consultations with Turning Points service users in England, all of whom had multiple needs, and some of whom had previously been excluded or disconnected from services. One was a man in his forties with a partner and 2 young children. He is diagnosed as having schizophrenia but also has a history of alcohol abuse and, at times, violent behaviour. His partner is also in touch with mental health services and their children have previously been on the at risk register.

A young woman with a severe learning disability, who had been in touch with a wide range of service providers, was often labelled as challenging, or as having a behavioural problem. She gets frustrated and sometimes aggressive which means that services are sometimes unable to deal with her (Edwards, 2003).

4.53. A typical form of non-engagement identified was that of an older woman living in the community who was eventually assisted through joint work. She had been affected by depression, the onset of dementia and malnutrition and could not deal with immediate dangers, such as a gas leak. She was affected by 2 types of transition – in her health, due to increasing dementia, and in her accommodation, given a series of moves from home to

hospital, to residential care, then back home to live with a live-in carer. While she did not accept help initially, gradually she accepted support from her GP, family and other services (CPN and specialist Dementia Home Care team), so enabling a 'joined-up assessment' (George, 2000a).

4.54.   A challenging version of 'non-engagement' in a case of suspected abuse of an older person was used to illustrate the need to balance the social work value of self-determination with risk assessments, external monitoring and involving the police in a timely way (Preston Shoot, 2002). An older woman had alleged physical abuse and food deprivation and was then assessed as doubly incontinent, with serious mobility difficulties and as unable to care for herself. Her GP had requested a housing transfer. Her family said they found her hard to help as she was unreasonable and demanding. Though social workers attended routinely and she continued to complain of family members' behaviour, she refused to go into residential care, or to have the police involved. Later she was beaten up and almost strangled.

4.55.   More generally a key challenge for staff is "the issue of how to engage people who refuse the support. How do we work with them?", as was raised in a recent study of intentionality in homelessness (Rosengard et al, 2006). This will be considered in Chapter Six.

Beyond eligibility

4.56.   People with multiple and complex needs, whatever their primary assessed need, may be 'defined out' of the remit of services because they are assessed as being 'too complex' or 'too challenging' for the service (Keene, 2001; Rankin & Regan, 2004; Bevan, 2003).   Such exclusions occur in statutory and voluntary sector services, including schools, residential establishments, housing support and other support services. They may impact on people leaving institutions and homeless people, people with disabilities, young people of school age services for people with a learning disability, people with addictions of all ages, or young people or women who have experienced abuse.

4.57.   A key block is that residential services may not accommodate people with additional needs, such as a diagnosed mental health problem. - "the services 'gate' may be closed, or only part open, when people are identified as having complex needs, or a history of difficult behaviour" (Rosengard Associates with Scottish Health Feedback, 2001). This may be either because the client group's needs are narrowly defined, or because staff are under-resourced and untrained to address specific additional needs or problematic behaviours. Or it may be that existing resources, such as shared accommodation, are inappropriate due to the assessed risks for service users or staff, for example where there are histories of violence or sexual abuse.

4.58.   Management strategies also vary in relation to client non-cooperation or non-engagement. While some services strive to operate as flexibly as possible, others appear to operate a more or less rigid, '3 strikes and you are out' policy, and apply this for example, when people fail to attend appointments or to keep to agreed plans. While in some instances there may be no option but to exclude the person in question, the net effect of a rigid style will be to reinforce the inverse care law - those most affected are likely to be those with the most chaotic lives.

4.59. There is stark exclusion in the case of asylum seekers from mainstream services due to the current law and their dependence on NASS[4] service provision while seeking asylum. Moreover they may be excluded forcibly from school, accommodation and support services, if their claim is unsuccessful. Here service providers have no choice, regardless of concerns about destitution or the distress of the individual. As well as the impact on individuals, there is a reported stress impact on staff (ECRE Conference in Glasgow, May 2006).

4.60. Clearly, exclusive agency policies may be modified over time with changes in the law or with organisational policies – for example, access to services for asylum seekers has decreased incrementally since 1999. Others affected by exclusions from services, have been young people using drugs and current alcohol users in 'dry' establishments. It is notable however that since the development of joint local homelessness strategies and partnership working with drugs services, homelessness services have gathered confidence in working with people misusing drugs in Scotland. Additionally there is the ongoing development of a wider and more responsive range of services for homeless people with serious alcohol problems (Rosengard et al, 2002; Neale and Kennedy, 2002).

4.61. The following example from Turning Point's Link Up service shows the importance of responsive and pro-active work and of services jointly striving and 'sticking with' a person who has been alienated from services and/or is not ready and motivated to engage with the services on offer.

A history of multiple issues and multiple service use
Dan was in his mid thirties and had a history of polysubstance misuse, mental health problems, homelessness and sexual abuse. He started sniffing glue at 17, was addicted to heroin at 18 and began to drink to excess. He was diagnosed with depression and schizophrenia at 16 and was admitted to hospital on a number of occasions because of mental health problems. He spent long periods drifting from hostel to hostel and being barred from most of them.

At 31 he was allocated a place in supported housing, where he lived for 6 years. He was happy during this time, didn't misuse substances and took his prescribed medication regularly. However, when the service changed its policy to permit residents to drink, he felt this was his downfall. He returned to polysubstance misuse and lost his accommodation. We shall see that this situation improved later (Turning Point unpublished report).

Influences on exclusion and non-participation

Exclusion and poverty
4.62. Exclusion and low participation in services is shaped significantly by the impact of poverty, and particularly on neighbourhoods with concentrations of high unemployment/low income, benefits dependence, poor literacy and low confidence in service use (Pantazis, Gordon and Levitas, 2006; Mooney and Scott, 2005; The Social Exclusion Unit, 2005 a and b). Moreover some groups are more at risk of poverty and unemployment, such as children and young people with intellectual disabilities, with negative consequences for the health and well being of their families (Emerson, 2004).

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[4] NASS is the Home Office's National Asylum Support Service.

4.63. In the face of a complex and changing welfare benefits system, those who are multiply disadvantaged and/or who have support and care needs are often greatly dependent on professionals to obtain and sustain the income support and benefits that enable them to live positively in the community and the care and support that they need (Hirsh, 2004). Moreover, fragmentation of services exacerbates problems when people's needs change, as when someone is hospitalised or enters a criminal justice establishment this can affect welfare benefits adversely (e.g. housing benefit) (Rosengard et al, 2002).

4.64. Receiving Direct Payments helps increase flexibility and individual control over outcomes and improves the quality of disabled people's lives (Witcher et al, 2000), although some recipients do not get the support they need to make this work well for them (Morris, 2004). Further, although Direct Payments can be used to buy a variety of support and services and not only to provide physical help with daily living, they have become synonymous with personal assistants and physical disability (Bornat, 2006).

Direct payments and mental health issues

An evaluation of a service initiative in Norfolk found that direct payments are described and designed in a 'discriminatory' way, as the language and ideas are most commonly associated with physical disability (Dawson, 2000). Research in Scotland (Ridley and Jones, 2002) found a low level of knowledge of direct payments among mental health service users and several barriers to their implementation including professionals' attitudes. Another author comments that recipients of direct payments fear that when their mental health improves their support hours will be decreased even though the level of support received is enabling them to cope (Morris, 2004). Other research has found that reductions in support hours have been experienced by some mental health service users (Davidson and Luckhurst, 2002 quoted by Morris).

Institutional discrimination

4.65. Agency non-recognition of particular needs or inaction in the face of excluding policies or practices can be systemic. Examples include where people with physical disabilities confront non-accessible buildings; where people's communication needs are unaddressed (people with learning disabilities; people from minority ethnic groups) and where cultural needs are not addressed sensitively (for example, minority ethnic groups, gypsy travellers whom the Scottish Executive treats as a distinct minority group) (Communities Scotland, 2003).

USER INVOLVEMENT

4.66. Generally there was very little focus in the literature on how far people with multiple and complex needs are involved at a strategic level in service planning and in the commissioning and management of services, although the literature overall emphasises the gap between the rhetoric and reality of inclusion for people with additional support needs. The gist of these discussions is that meaningful participation is variable, with some service users feeling that their views are not heard or taken into account.

4.67. There are indications that people with multiple and complex needs may be excluded from partnership and involvement initiatives because services segregate people according to

their impairments and therefore highlight their differences rather than shared experience (Clare and Cox, 2003; Morris, 2004). Additionally, those with multiple and complex needs may be seen as difficult or resource intensive to involve. As a result "marginalisation is the context in which many people with complex needs currently engage with health, housing and social services" (Clare and Cox, 2003).

4.68. Moreover, where communication difficulties are a constraint, staff may not have the conviction, the skills required or the ability to access resources to enable or maximise participation.

Children and young people

Professionals may not always take the steps required to hear children's views, just as Jenny Morris found for children with multiple needs whom she describes as 'silent consumers of health care' (quoted in Stalker et al, 2003), while Linda Ward (1999) suggests that 'the more complex the child's needs, the greater the gap between policy and practice may be' (Ward, quoted by Stalker, 2003).

4.69. Sustained participation requires continuing commitment, resources and support. White and McCollam state (1999) that "participation and consultation demand a great deal of effort and energy from service users, which will only be sustained if the exercise is perceived as useful and fruitful". They stress that engaging service users in planning will be undermined if this is "mere window dressing", with decisions in fact being taken elsewhere; and that "consultation fatigue may begin to prevail amongst staff and service users".

4.70. There have been advances in structured user involvement in strategic planning through the Scottish Executive's engagement in pro-active consultation with homeless people and community care service users. This was evident in examples such as the 'Same as You' consultation programme, which involved people with learning disabilities, the Millan Review consultation with mental health service users (Rosengard and Laing, 2001), Communities Scotland homelessness service inspections (Communities Scotland, 2005) and the Homelessness Task Force consultations with homeless service users. There were no indications however of progress in service user involvement in the purchasing and commissioning of services.

OUTCOMES

4.71. Here we turn to consider what the literature overall tells us about the outcomes of service interventions for people with multiple and complex needs. Four key points emerge:

- The literature raises questions about how outcomes can meaningfully be defined and measured, and particularly given the focus on people with changing needs
- It offers little systematic evidence of outcomes of the type, for example, that has been based on monitoring information
- Given that most research is short-range and qualitative, or offers 'snapshot in time' quantitative study findings, there is no comprehensive or systematic information on longer-term outcomes.
- Case study histories are frequently used to illustrate patterns over time.

4.72.   Regarding the problems of defining outcomes, questions arise such as: Is sustained outreach contact an output/ process or can it be viewed as an outcome? Is a client's move on to housing coupled with support an output or an outcome for people who have had revolving door histories? Can continued drinking in permanent accommodation be regarded as a positive outcome for someone with chronic alcohol misuse? Does a young person from care who has had a troubled history and has rejected support at times, but is continuing to receive continuing support while staying in an unsuitable Bed and Breakfast establishment, have a positive outcome?

4.73.   Although poor outcomes appeared to be prevalent, some positive outcomes were clearly identified in the literature. For 3 of the people whose problematic histories were described earlier, there were positive outcomes, as shown below.

> Over time John received help from various services, including hostels, residential care, counselling and support and medical staff. At the time of the interview he was in sheltered accommodation, where he had settled well and did computing and other courses. He was getting married. (Adapted from Routes Out, 2002)

> Peter, the young homeless man, was befriended by a man he had met in prison. He offered to meet him on his release and help him find accommodation. He put him up for 13 weeks and then found him a place in his current hostel. At the time of the interview he had 'kicked his drug habit' and is looking forward to 'making the best' of his life. (Cloke et, al 2002)

> When Dan first presented to the Turning Point crisis service he was vulnerable, distressed and malnourished. He had been in a DSS hotel, but left to live on the streets because of bullying by other residents. He was admitted and stayed for 4 weeks during which staff ensured that a care manager was in place.
>
> His physical health improved dramatically and he gained one and a half stones in weight. His mental health also improved and his confidence grew. He interacted well with other residents and participated in many activities and trips. He did his daily chores, often assisting other residents who were ill or tired. In his third week he bought a guitar and played it in the garden each day. He needed accommodation with support for his mental health and substance misuse problems and was referred to SAMH's Connect service. This found him suitable accommodation after a month. During that time he relapsed and was readmitted to the crisis service for 12 days detoxification to stabilise him. Connect then worked with him to find supported accommodation.

4.74.   This man's experience mirrors a dynamic identified by Rankin and Regan (2004) and other research (Keene, 2001) – that often it is not until people are ready and motivated that positive engagement occurs. This affirms the need for agencies to 'stick with' people over time.   While this may indicate long-term and high support costs, the alternatives of 'giving up' on people is to risk serious crises with associated higher cost outcomes for some.

4.75.   It was not feasible in this study to gather agencies' reports systematically.   Had it done so this may have supplied information about evaluations conducted and more detailed evidence on monitoring.   However, Rankin and Regan (2004) and Keene (2001) both identify a lack of systematic or sophisticated monitoring or tracking of multiple and complex needs and of monitoring the effectiveness of services.

KEY POINTS – CHAPTER FOUR

- The attitudes of staff in a range of services can be experienced as off-putting, insensitive and unhelpful and this undermines service users confidence and trust

- Community care service users and carers are often not familiar with their entitlements to assessment or with its role in support planning. Moreover, the multiplication and fragmentation of services leads to fragmented and multiple assessments, a source of stress to service users

- Where services define and apply their client group criteria inflexibly, such as arbitrary age cut off points, this mitigates against continuity of care

- A 'silo mentality' constrains the achievement of co-ordinated support and risks people receiving inappropriate services with poor outcomes. Medical 'dual diagnosis' labels in particular can limit the range of options accessed by people with multiple and complex needs

- Overall, it appeared that the presence of multiple, interconnected needs, rather than the severity of needs, creates the greatest challenges for services created to meet single service user needs

- Often there appeared to be inadequate assessment, support planning and resources for people affected by transitions. This delayed people gaining access to the services that they needed, or limited their rights

- When service users and carers disagree with professionals' assessments, the options selected appear to be constrained by resources or limited vision

- People from minority ethnic communities, refugees and asylum seekers did not consistently receive sensitive assessment or access to interpreters and translators

- People with multiple needs may be 'defined out' of the remit of services for organisational reasons, because they are assessed as being 'too complex' or 'too challenging' for the service

- Non-engagement with services occurred because of dispositional, organisational, situational and structural factors. These included: lack of trust and confidence, services' cultural insensitivities; services' systems or cultures being compatible with life-styles; poverty impacts, and people not being ready to address problems. Outcomes may be exclusion and rough sleeping exacerbated by poor health, injuries, or institutionalisation

- Exclusion reflected the interplay of poverty and related disadvantage and additional support needs. Refugees experience significant exclusion and require highly sensitive, targeted services

- There is a gap between the rhetoric and the reality associated with participation in services.

4.76. The following summary table identifies what the literature tells us, first about the key processes and influencing factors on service users' experiences in relation to moving on within and through services (column 2). It then summarises elements of good practice required to enable positive experiences and outcomes (column 3).

Table 4.1. Influences on experiencing services and good practice implications

Pathways stage	Processes/influencing factors	Service requirements
Getting through	Motivation and readiness influence engagement and process Assessment and access criteria influence support outcomes variably Professional divides and approaches meet needs variably Users may lack clarity re service roles and systems Extent to which services address individual & cultural needs and circumstances sensitively affects support Structural factors may limit engagement Management policies may limit engagement or result in evictions and exclusions Joint work & information sharing may be poor and result in poor outcomes Monitoring and review of progress is important Funding streams and stability are critical to continuity	Joint assessment systems Holistic, participative support planning & review Cultural sensitivity Quality communication Positive, collaborative care management User involvement/ engagement opportunities Preventing homelessness/ exclusions Active outreach Known user satisfaction and preferences Establishing creative options with service users Well networked services Joint work, partnerships, protocols Creativity and flexibility Collaboration in monitoring and review
4 Getting on	Motivation, readiness, preferences Resettlement approaches may be restricted by service fragmentation; approaches orientation and practice Access to appropriate, sufficient follow on resources is uneven Income/ sustainability is critical Sophisticated monitoring and review is needed to monitor outcomes	Creative options established with service users Onward referral system based on knowledge of relevant resources User purchasing systems enable user choice; increase options Joint work, networking and protocols e.g. information sharing Joint planning to meet identified gaps

CHAPTER FIVE: SUMMARISING THE GAPS

INTRODUCTION

5.1.   The report so far has focused on how people with multiple and complex needs access, experience and move on within and from services. This overview has generated an emphasis on deficits and gaps in services, rather than on existing and potential good practice. This chapter aims to summarise these gaps and deficits and the associated problems that the literature has identified in regard to joint working, and to clarify related influences and implications. Before moving on to focus specifically on good practice in Chapter Six, this chapter will conclude by considering what the literature tells us about what service users want.

THE GAPS

5.2.   Overall, the problems and their recognition are not new; nor are they specific to Scotland or the UK. What emerged from the literature however is that there is a renewed attempt to clarify and tackle the systems and other influences that undermine positive responses.

5.3.   Reinforcing the findings to date, Rankin and Regan (2004) identify 4 key gaps in services for people with multiple and complex needs:

- Services fail to recognise the inter-connected needs of individuals and how their needs relate to the influences of poverty and social exclusion
- Services are fragmented and even those that strive to be holistic are often organised around single needs or issues
- Planning to meet needs often does not address housing and employment issues
- Area based initiatives to tackle social exclusion are often disconnected from social care policy.

5.4.   And showing that similar deficits are found beyond the UK, the Human Service Department, Australia (2003a) identified:

- Ineffective service responses, including lack of or poor collaboration and communication among services and staff
- Difficulties in locating suitable accommodation
- Absence of a case manager or difficulties with their case manager was a key issue
- No appropriate day services
- Services are fragmented
- "Funding criteria do not allow for services to extend beyond the brief".

5.5.   Below we discuss a number of key themes in relation to the gaps identified in this review. On the service provision side these include: a lack of strategic prioritisation; fragmentation at national and local levels, in local planning and commissioning and in professional assessments and support; indications of a lag in pursuing the benefits to be

gained from joint working or what is termed 'collaborative advantage'; poor communication and information flow; lack of support for user participation; limited approaches and narrow vision and short-term time-frames and crisis driven approaches.

5.6.   Additionally, on the service user side particular needs and circumstances may result in language and communication blocks, and some people may be reticent to disclose in the context of stigma. While stigma is a cultural and external influence rather than an individual issue, another major external constraint on services and service users' opportunities is that of resources.

5.7.   In sum the balance of these influences and constraints is such that problems stem from service systems, approaches and resourcing rather than with the multiple and complex needs of service users. The constraints are considered in sequence below.

Lack of strategic prioritisation

5.8.   The 'Mind the Gaps' report (SACDM and SACAM 2003) commented that despite recent positive policy developments focused on improving mental health services, these have not yet led to:

- Consistent improvement across the country in collaborative planning, or in the delivery and accountability of services for people with co-morbidity, including those with mild to moderate ill health
- Professional consensus on the role of secondary mental health services in the treatment of personality disorder in Scotland
- Systematic Scottish Guidance and notable advances in service provision. There is a lack of systematic service provision for people who have survived earlier traumatic experiences. (SACDM and SACAM 2003).

5.9.   While many authors have identified a similar lack of strategic prioritisation as an inhibitor of the effective joint work required to address multiple and complex needs well, there has emerged an expanding body of relevant Guidance produced by the UK Government, the Scottish Executive and generated from research reviews.

Fragmentation – central and local

5.10.   The account of the literature so far stresses that fragmentation is the key driver of problems that include partial and inconsistent planning and service responses.

At central government level
5.11.   Funding regimes are fragmented (Petch et al, 2000). In England, for example, drugs issues are funded via the Home Office due to links with the crime and disorder agenda, whereas alcohol issues are the responsibility of the Department of Health and reflect health and medical agendas, while domestic violence services for survivors are funded through the voluntary sector etc (Humphreys et al, 2005).

At legislative level
5.12.   While current legislation increasingly emphasises the need for joint approaches and cross-referencing, it must be recognised that services working with people with multiple and complex needs have to consider a fragmented though interconnected legislative framework,

with individual pieces of legislation relating to particular needs (for example, the Disability Discrimination Act 1995; the Mental Health (Care and Treatment) (Scotland) Act 2003; NHS and Community Care Act 1990; the Children (Scotland) Act 1995; the Community Care & Health Act 2002; the Homelessness etc (Scotland) Act 2003 and the Asylum and Immigration Act 2004).

5.13.   While legislation encourages and enables co-ordinated planning at local level in all these areas, the framework for pooled finance and joint commissioning remains under-developed, and Stalker et al (2003) point out that the Health & Social Care Act (2000) in England allows stronger 'flexibilities' than the Scottish legislation in regard to these.

At professional assessment and support level
5.14.   The common syndrome is that a variety of professionals may each be regularly in contact with each client, with each of them addressing people's needs through the lens of their particular specialism. Moreover people go through multiple assessments – 'assessed to death', while poor outcomes result, such as inappropriate hospital discharges to hostels.

5.15.   On the other hand it does not follow that the fact that people receive several different support services is always perceived negatively. Some people with multiple needs, and particularly at points of crisis or turning points, appear to value the input of various services, provided that these are co-ordinated (Rosengard and Scottish Health Feedback 2000). One young woman, who had been a long-term drug user and been working as a prostitute, was assisted to move on positively by a variety of voluntary and statutory agencies; she commented – "its nice. It shows someone cares" (Society Guardian: 12.07.06.)[5].

At local planning level
5.16.   The composition and scope of particular partnerships may exclude key players – for example where social work, health and education are involved in joint planning, but the absence of housing representation undermines assessment of housing implications (Beresford and Oldman 2002; Stalker et al, 2003). Other instances of such exclusion have been where education was not involved in community care planning (Dean et al, 1999) or where voluntary agencies or service users/ local residents have been excluded from area improvement partnerships (Mayo and Taylor, 2002).

Commissioning
5.17.   Commissioning is the process through which strategic and funding bodies (local authorities and health boards and central government agencies, such as Communities Scotland, for example) authorise an agency to develop or carry out a service. The process of commissioning requires the strategic assessment of needs to be addressed; planning to meet these needs; the contracting or purchasing of services and the monitoring of the effectiveness of these. Given the growth of a health and social care market since the 1980s and the increasing need for a diversity of community based services since the de-institutionalisation brought about by the implementation of the NHS Community Care Act in 1993, there has been a proliferation of providers. Commissioning is therefore a competitive process.

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[5] Articles on Louise. SocietyGuardian.co.uk/crimeandpunishment

5.18.   The difficulties with the commissioning process have been identified by Rankin and Regan (2004), Hudson (2005) and others:

- Commissioning is not sufficiently comprehensively strategic and needs assessment and planning has been partial and ineffective, with commissioners focusing on purchasing and supervising services, rather than on strategic aspects
- Boundaries of health and social care commissioners and providers are not consistent and commissioning partners may use different funding models, such as 'block' (several services) or 'spot' (particular services) purchasing
- Commissioning has been conducted in a fragmented way, and the re-structuring of services has impeded co-ordination, although there has been movement towards joint commissioning
- Funding itself is fragmented, with sources being from both central and local government
- There is not always a 'needs-led' approach, nor a holistic approach
- There is uneven consultation and involvement with the voluntary sector. Voluntary agencies and housing associations often feel excluded from the process of planning and developing services (Edwards, 2003; Rosengard et al, 2001)
- Preparing bids is a demanding, resource intensive process and small providers find it difficult to compete
- Contracts are generally for one to 3 years, and this inhibits planning and increases costs for providers
- More attention is required to local workforce development needs.

5.19.   At a strategic level therefore Keene states,

"Professionals (like planners) assess predefined needs in their specialized populations, using criteria and priorities which are pertinent to their specialisms. They do this in isolation from each other" (Keene, 200,1 p.6).

5.20.   Additionally Hudson (2005) points out that user-led commissioning, such as direct payments, may be persistently in tension with centralised commissioning, as here service users determine and purchase the services provided.

Problems in creating collaborative advantage

5.21.   Obtaining 'collaborative advantage' when working in turbulent contexts is a key driver towards joint working, although this is not without its problems (Huxham, 1996).

Power and commitment
5.22.   Agency representatives around the planning table often lack the power and authority to make decisions, or they are unevenly matched in their delegated authority and commitment (Dean et al, 1999; Petch et al 2000). Moreover, progress can be undermined by personnel changes across partner agencies (Flint et al, 2001; Dean et al, 1999), and despite evidence of some positive outcomes, some partnerships are formed too late to arrest problems, including processes of area decline (Flint et al, 2001).

Discordant remits and culture clashes

5.23.   The tensions that impede effective partnership working have been found to result from:

- Incompatible agency boundaries and time-scales
- Agency remits inadequate to the complexity of the problems, particularly in high stress areas (Flint et al, 2001)
- Communication problems arising from contrasting agency cultures, perspectives, practice and knowledge bases (Ambrose, 2001; Mayo and Taylor, 2002; Humphrey et al, 2005)
- The poor briefing of agency representatives on other agencies' roles and responsibilities. (Dean et al, 1999)
- Commissioning structures and systems that encourage competition rather than collaboration between agencies (Rankin and Regan, 2004).

Co-ordination problems and information flow

5.24.   Today, agencies are extensively required by statutory funders to assess needs for planning and funding purposes, and to do so in a holistic and comprehensive way, whether in regard to community regeneration/ community planning (Ambrose, 2002) or to address community care or homelessness-related needs (Balloch and Taylor; 2002, Keene, 2001).

5.25.   Joint planning requires partners to research and pool information on needs and demand for services, to map the existing supply of services, to assess critical gaps and develop a strategy or programme for addressing these gaps.

Example of information and co-ordination deficits

Two Rowntree studies, one of which focused on the housing needs of disabled children (Beresford and Oldman, 2002), and a second that focused on disability amongst refugee and asylum seeking communities (Roberts and Harris, 2002), highlighted significant gaps in the co-ordination and flow of information about impairments.

The impact of this was to inhibit effective care planning. This was particularly problematic where people were moved between areas, as in some cases of people being resettled from hospital, or in the case of asylum seekers whose disabilities may have resulted from torture. There also appeared to be no system in place for informed communication between NASS and receiving local authorities on the additional or multiple needs of refugees being dispersed. Additionally, movement into areas could put extensive pressure on local resources and teams.

5.26.   Overall, the joint planning experience highlights problems experienced in accessing required information, and indicates that information sharing is poor. (Petch et al, 2000; Northmore, 2001 p 97; Ridley Associates, 2004).   Keene (2001) similarly stresses that the lack of accurate inter-agency data inhibits both the development of informed planning and a systematic context for developing "inter-professional or multi-agency working" (Keene, 2001, p32).

> **More on information deficits**
> Lack of information on service use patterns restricts effective planning, emphasising that "easy access, multi-problem agencies", such as A&E departments and Primary Care Trusts, in fact need to link with a range of agencies to clarify use patterns. As a result *"recent controversies about inappropriate patients are being reformulated in terms of inappropriate service provision"* (Keene, 2001, p33).

5.27.   Other problem areas identified in relation to information flow include that agencies working together often have a lack of knowledge about the relevant service network, there may be a lack of openness and trust between agencies working with the same person, and joint work is inhibited by a lack of protocols on matters such as information sharing and confidentiality (Keene, 2001, Rankin and Regan, 2004).

5.28.   It is notable that recent Government reviews and good practice guidance, which will be addressed in the following chapter, have increasingly absorbed these arguments.

Lack of support for user participation and choice

5.29.   In Chapter Four we saw that the literature identified movement towards a greater involvement of service users in needs assessment at the individual level. However, progress appears far slower in regard to empowering and meaningful user participation at a strategic level. Again the pace has been set by the developmental approach in the learning disability field in Scotland (Scottish Executive, 2000).

> **Right to complain**
> Awareness of the potential to complain also appears to be limited. Hardy and Young point out that few older service users and carers are aware of how to make complaints if they wish to do so, and few in fact want to complain, as they "were 'grateful' for the help they got" (Hardy and Young, 1999).

5.30.   Access to the user led purchasing of care such as direct payments has been uneven across client groups and generally slow in Scotland compared with UK wide, as highlighted in Chapter Two. Arguably, the lower take up in Scotland reflects political and cultural issues as well as a lack of appreciation of their role amongst professionals and service users. Pearson (2006) suggests that resistance has stemmed from the mixed economy of care and the concerns raised by union workers and some practitioners, which have been more prominent in Scotland than in the rest of the UK (Pearson, 2006). This indicates the need for a co-ordinated promotional strategy to promote equitable access, and this issue will be addressed in Chapter Six.

Limited approaches and narrow vision

Silo mentality
5.31.   Stemming from fragmentation, 'silo'-bound approaches encourage singular problem responses rather than a holistic, whole person approach (Keene, 2001; Rankin and Regan, 2004; Baron, 2005; Humphrey et al, 2005 and Noel et al, 2005).

5.32.   Narrow frames of reference in turn limit the scope and continuity of help for people with complex needs, "with little regard to co-occurring problems" (Keene, 2001: p52).

Service users' experiences
Edwards (2003) highlights the impact on service users' experiences of professionals' restricted vision. One such example was a psychiatrist who addressed a woman's mental health problems but not an eating disorder. A young offender who was on a drug intervention programme, then received no help with housing, with getting a job, with staying off drugs or with accessing education opportunities.

Service users often commented on the length of time it has taken to obtain the services that they need that might make a real difference to them, and Edwards describes how one service user who was suffering from anxiety, paranoia and lack of confidence saw a psychiatrist and CPN for 8 years before gaining access to the practical support she needed to tackle everyday tasks.

5.33.   Solutions may be standardised and based on existing resources and past experience, rather than creative approaches to meeting individual needs. This can lead to reliance on large residential units and uniform day services, which are only currently in the process of reprovisioning (Edwards, 2003 & Petch et al, 2000).

Skill & competence deficits
5.34.   Skills and competence deficits emerged throughout the literature in regard to professionals' awareness of particular and multiple needs. A critical need emerged for awareness training for staff to understand the spectrum of people's needs and their interconnectedness, and to appreciate the perspectives and impact of other professionals working with the same clients (Humphreys et al, 2005; Rosengard et al, 2002).

Some examples
Staff working with people with dementia may have little awareness of older people's differing sexual orientations (Manthorpe and Price 2003). Whilst services may choose a single issue focus to prevent 'muddying the waters', the downside is that connections are not recognised – for example, not recognising that treating substance use might resolve other problems (Humphreys et al 2005).

Additionally, poorly integrated service approaches are compounded by training deficits. For example youth justice may see child sex offenders as requiring a control regime, while child protection sees them as victims requiring support. Joint training is therefore crucial for understanding interconnected needs (Masson, 2003, 2004).

Short-time frames and crisis-driven assessment

5.35.   We have seen that people's emotional traumas do not emerge in initial assessments and that often addressing practical needs is the priority (Okitikpi and Aymer, 2003, Hopkins and Hill 2006**).**   Additionally, where a crisis is a precipitator to assessment, this may on one hand widen the scope of the assessment (multi-agency case conference), while on the other it may be dominated by the need to obtain a crisis resolution (George, 2000 a,b).

Language and communication blocks

Minorities

5.36.   Language can be a critical barrier to receiving services in minority ethnic communities (Thoburn, Chand and Procter, 2005).   One service user quoted commented "if you can't speak English they won't deal with you properly – its degrading" (O'Neale, 2000, p15, quoted in Thoburn et al, 2005).

Communication difficulties

5.37.   Although there is a significant chance that some people with learning disabilities will develop mental health problems, they may be less likely to be diagnosed with depression or emotional disorders.   Russell et al (2000) suggest that diagnosis of clinical depression may not be triggered until there is a crisis, such as a violent incident, while family and friends also frequently fail to spot depression.

> **Good practice point**
> Bradshaw stresses that communication difficulties can be overcome for people with a learning disability even when people have additional needs, such as dementia, sensory impairments or challenging behaviour, although this requires resourceful, person-centred planning and support (Cambridge et al, 2005, Chapter 8).   The message from several case studies which illustrate the use of a variety of communication tools, such as mats, Makaton, and multi-media packages, is to stress that effective communication is achievable despite multiple disabilities.

Client's reticence to disclose in the context of stigma

5.38.   Stigma may inhibit people's willingness to disclose their problems and the influences of these in the assessment process, so emphasising the need for skilled and sensitive assessment interviews, as well as confidence-building in the support services on offer is needed.

> **Examples**
> Baron (2005) states that women who have experienced abuse "already suffer from the stigmatization and social isolation".... "Those who have a mental health diagnosis or who are labelled as alcoholic or 'drug users' may find it even harder than other women to report, or even to name, their experience as domestic violence".   Stigma in fact is likely to inhibit communication by all those who have experienced sexual abuse and violence, including those from refugee and minority households (Hendessi, 1992; Rosengard and Jackson, 2005).

Resource constraints limiting outcomes

Inadequate & inappropriate resources

5.39.   An underlying constraint on achieving positive outcomes identified throughout the literature relates simply to the inadequacy and inappropriateness of the range of resources on offer to meet multiple and complex needs.   Clearly this is a key issue for all service users. A senior social work manager quoted in one study commented that community care assessment is budget driven (Barr et al, 2001) and other studies suggest that resource constraints may restrict positive accommodation and support outcomes for people with complex needs, as reflected in the following quote:

> *"Moving towards individualised solutions for everything is inevitably more expensive. One care package increased from £5,000 to £85,000 for example – it's just not sustainable for everyone" (PiP Chair quoted in Ridley Associates, 2004, p80).*

5.40.   Resource issues were often a source of tensions between agencies that seek access to accommodation and support for clients and targeted service providers.   Many studies highlight that resolution for individuals can depend on advocacy by family members, referring agencies or by independent advocates who facilitate a more flexible approach on the part of the service provider.

5.41.   In the longer-term, resolution of these deficits may require joint strategic planning and increased resource allocation to meet specific gaps, such as small and personalised supported accommodation services, 'wet hostels' where people continuing to drink alcohol can stay, or services with staff that are trained to work intensively with people with multiple or complex needs, whether they are living in ordinary housing, with families, or in residential services.

Examples of resource constraints

Key studies have found that needed resources were difficult to access in the community and to sustain ordinary living and that there was a notable shortage of good quality specialist services (Beresford & Oldman, 2002; Stalker et al, 2003).   Moreover, if specialist resources were accessed, there was pressure to move on (Stalker et al, 2003).

Some young people were in inappropriate resources, such as those with a learning disability in mental health establishments.   Additionally, some people with learning disabilities who had been admitted for in-patient assessments in learning disabilities services remained there for up to 2 years.

Short-term funding can also inhibit effective planning and the continuity of services (Cunningham-Burley et al, 2005).   Another inhibitor is the lack of a framework to pool resources (Petch et al, 2000, p 80).

5.42.   Whilst learning disability services have set the pace in terms of person-centred planning, outcomes are still dependent on joint planning and resources.   One strategic needs assessment study for 3 local authority areas in regard to people with a learning disability as

well as additional needs, found good practice alongside gaps and deficits (Ridley Associates, 2004).

- People with more complex needs were in the minority in supported employment services and most likely to be in specialist day centres or day hospitals
- 'Short breaks', recognised as a key coping strategy for families caring for someone with "profound and complex needs", were rarely available and insufficiently flexible
- Inequalities in access to primary health care by people with learning disabilities were exacerbated by the presence of additional needs
- A lack of suitable housing and support provision for people with more complex needs resulted in a some people being placed out of the area at high cost.

5.43. Similar deficits have been highlighted by other research in relation to different client groups:

- A lack of accessible accommodation and/ or specialist equipment for people with disabilities (Prewett, 2000)
- A lack of suitable short break caring for families of children with complex health needs, because of a lack of suitable carers with the right training and background, coupled with the fact that some young people require the presence of 2 carers (Prewett, 2000)
- A lack of gender sensitive and empowering services for people with learning disabilities and others with multiple problems who self-harm. This requires recognition that agencies' approaches may increase self-harm, understanding people "in the context of their whole lives" and ensuring that they have the opportunity to determine ways forward themselves (Warner, 2005, p6; Community Care 'best practice', 2006).

5.44. Additionally, a wide spectrum of gaps and deficits in service provision for homeless people with additional support needs has been identified through strategic reviews conducted for local authorities, and for partners in the development of homelessness strategies under the Homelessness (Scotland) Act 2001 (Rosengard et al, 2001, 2002, 2003) In sum, the options for homeless people with additional needs were restricted by the lack of access to suitable resources, as well as by other service deficits, including the need for:

- Improvements in information and advice services
- Person-centred, holistic approaches and related training
- More pro-active and targeted outreach support (including streetwork)
- Additional, more intensive and more flexible housing-related support services
- Specialist residential resources to meet particular needs and
- Increased and better joint inter-departmental and inter-agency working.

5.45. Focusing on the ways in which people with disabilities are excluded from full citizenship, Morris (2005) quotes a parent of a 19 year old daughter who has significant cognitive impairment, who said:

"The lives of people like Elinor hold up a mirror to the values of our society. You've just got to look at the life of someone who has a label of 'profound and multiple learning disability' to see that society's reaction to her has been

driven by an unwillingness to make sufficient resources available to enable her to have as good a quality of life as possible" (p37).

5.46. Overall, the literature highlights the need for a full range of service options to be on offer to those with multiple and complex needs. While in relation to most care needs good practice has emphasised ordinary living and community-based models of care, residential care services and supported accommodation may be relevant for some groups, and particularly so to meet the transitional needs of, for example, women fleeing abuse, vulnerable young homeless people or those leaving care who are not ready to move into independent tenancies (Rosengard et al, 2002, 2006).

5.47. In sum, the account of the literature so far presents a bleak picture of typical service pathways and experiences for people with multiple and complex needs. It suggests:

- A high variability in terms of the quality and personalisation of response
- That power in determining outcomes rests largely with professionals and officialdom
- That bureaucratic structures, together with fault lines in systems and professional divides, limit innovation and flexible responses, and
- That both professional planning and service user options and choice are highly constrained by available resources and regulatory constraints.
- That there has been a lack of strategic recognition, prioritisation and targeting of multiple and complex needs, although this appears to be changing.

WHAT DO PEOPLE WITH MULTIPLE AND COMPLEX NEEDS WANT FROM SERVICES?

5.48. It is important at this stage to reflect on what the literature tells us about the things that people with multiple and complex needs value about services and to draw on what appeared on the whole to be limited evidence of their positive experiences. Jenny Morris's excellent summary of what "people want from services", based on a survey of 83 people with physical disabilities and mental health problems and 25 interviews (Morris 2004), resonates with the experience of service users covered in this study and she similarly refers to "sparse evidence" of positive experiences. This offers a lead to representing the preferences of people with multiple and complex needs, based on the findings of the wider literature review. In doing so we supplement Morris's key findings by drawing on other literature.

5.49. Overall the literature review indicates clearly that service users would want:

A personalised, sensitive and holistic or comprehensive approach
- Staff who listen and believe and treat users with respect, valuing their views (Morris, 2004; Rosengard and Jackson, 2005; Crisis, 2005)
- Staff to treat them as "a whole person" and consider the range of their needs, while at the same time treating them as a person and "not as a disease" – a reason that homeopathy and alternative therapies were valued by some (Morris 2004; Crisis 2005)
- Services to be person-centred and flexible or 'open-ended' rather than the service user simply having to 'fit in' - services that 'stick with you' over time (Morris, 2004; Rosengard, et al, 2002; Crisis, 2005)

- Staff to be non-judgemental – "they accept you as you are" (Morris, 2004)
- Holistic assessments that take account of the range of users needs (Morris, 2004; Rosengard et al, 2002; Crisi, 2005)
- Not to have to repeat your story over and over again to different professionals – this can call up the pain (Morris, 2004; Rosengard et al, 2002; Rosengard and Jackson, 2005)
- Staff who understand and have positive attitudes to service users' particular needs and circumstances (Rosengard et al, 2001, 2006)
- Services to recognise that barriers to access and to moving on may affect people's mental health and physical health (Morris, 2004; Hudson et al, 2005)
- That mental health professionals responding to people with a physical disability as well as mental health needs take account of medical treatment for their physical condition (Morris, 2005)
- That extremely problematic personal circumstances such as physical access needs (Morris, 2004) or having had to flee another country or to escape abuse are taken into account (Thoburn et al, 2005; Perry, 2005).

Access to ordinary living, independence and positive opportunities
- Easy access services, including: prevention and early intervention (Scottish Executive, 2004b); information and advice; easy access technology; and decent accommodation (MacDonald, 1999; Morris, 2004; Hudson et al, 2005)
- Responsive advice and support (Morris, 2004), including ordinary housing and support models (the preference of most) and access to a range of services in the community with shortened waiting times
- An adequate income (Hudson et al, 2005)
- Opportunities to contribute to the community (Hudson et al, 2005)
- Support for informal social networks (Hudson et al, 2005)
- Safe and secure environments.

Co-ordination of their case
- Someone to co-ordinate the work of different professionals and counteract the negative impacts of fragmentation (Morris, 2004; Rankin and Regan, 2004; Rosengard et al, 2006)
- That staff communicate with and work with other professionals to meet their needs (all studies).

5.50. Having focused on the interconnected problems in service provision that undermine opportunities for people with multiple and complex needs, we now turn our attention to developing a positive service framework for addressing multiple and complex needs. In this pursuit Chapter Six will explore key themes of good practice identified in the literature. Chapter Seven will conclude this discussion with a summary of good practice principles, drawing out the implications for policymakers and service providers.

KEY POINTS – CHAPTER FIVE

Key problems and constraints on effective responses to the needs of groups identified as having multiple and complex needs were explored. These included:

- The lack of strategic prioritisation at central government level, although there is an expanding body of relevant guidance

- Service fragmentation is at the root of poor responses to multiple and complex needs. This can be seen to reflect the drivers of bureaucracy, specialised professionalism and the multiplication of services. The consequences of fragmentation are evident in funding regimes and legislation focused on particular needs; in professional assessment and support systems and in local planning and commissioning systems

- Impediments to partnership and joint work limit collaborative advantage in responding to multiple and complex needs. This occurs where key players are not represented, or there is a lack of strategic commitment at the joint planning table; when there is inconsistency in terms of agencies' planning time-frames, boundaries and resources; if partners remits are too narrow to address multiple and complex issues; when there is inadequate information about each others' roles and remits and where commissioning systems promote inter-agency competition rather than collaboration

- Despite the movement towards joint planning and the growing recognition of the need for joint working, lack of co-ordination and poor information flow inhibits both strategic planning and effective care planning for all groups with multiple and complex needs

- Features of funding and commissioning systems, organisational systems and cultures interact to undermine effective joint working and outcomes. These include: discordant agency remits, professional and agency divides and culture clashes; limited approaches and narrow vision; short-time frames and crisis-driven assessment

- There are indications that the movement towards participatory approaches in care planning for individuals are not matched by progress in collective participation of people with multiple and complex needs as service users and citizens. Additionally there is scope to increase awareness of rights to complain. This will require leadership at policy and managerial level

- Stigma, which may be a wider cultural issue may inhibit appropriate and full disclosure of people's problems, and this needs to be acknowledged by providers. Cultural and political issues – politics with a small 'p' – also appear to have inhibited the take-up of direct payments

- While language deficits can inhibit appropriate service responses for minority groups, other communication blocks limit positive outcomes for people with disabilities, including learning disabilities, sensory impairments and dementia. These problems can be overcome with sensitivity and appropriate resources.

5.51. The chapter then focused on valued aspects of services, as identified by service users in the literature. These ranged from person-centred approaches that treated people with respect and sensitivity, to the scope to access a range of responsive services in a co-ordinated way.

CHAPTER SIX: IMPROVING PRACTICE AND OPPORTUNITIES

INTRODUCTION

6.1.   Having focused on the interconnected problems in service provision that undermine opportunities for people with multiple and complex needs, we now turn our attention to developing a positive service framework for addressing multiple and complex needs. In this pursuit we build on the literature review findings on what service users, professionals, commentators and policy makers have identified as key themes in good practice.

INCREASING AWARENESS OF SERVICES

6.2.   As noted in Chapter Three, people need to be aware of the existence of services that can help them. A number of studies have reported that finding out about available services, what they do, who and how they can help, is very difficult for existing or prospective service users. (see for example Scottish Executive, 2005e,f,g, and 2006a,b,c; Social Exclusion Unit, 2005a; Jarvis, 2005; Keene, 2001; Crisis, 2005 and Hardy et al, 1999).

6.3.   While many people have difficulty in finding out what services are available, some are known to experience greater difficulties than others (Social Exclusion Unit, 2004a and 2005 a, b).

Access to information and advice

6.4.   Overall, there is increasing recognition of the range of information and advice that may inform expectations and guide choices for people with multiple and complex needs. To maximise inclusion this requires access to the full range of information, along with the advice and support required to enable service users to participate actively and meaningfully in influencing their futures and the design of services.

> **Good practice points on information provision**
>
> The range of information requirements highlighted relate to:
>
> - Information about agencies' needs assessment systems as well as on assessments of service user options for accessing and sustaining housing, support, day services, community facilities, health services, welfare benefits, education, training and employment (Communities Scotland, 2000, 2003, 2004; Scottish Executive National Care Standards, 2003).
> - Information about people's rights and obligations as service users
> - Information about access to good quality translation and interpreting for minority ethnic groups/ refugees (Scottish Consumers Council, 2005; Communities Scotland, 2000, 2003; Roshan, 2005)
> - Information about financial planning and welfare benefits (including direct payments) and insurance (in the case of health conditions) (National User Network et al, 2003)
> - Information about the implications of health conditions for people's existing and future work lives (SHA, 2005)

- Information about health testing in regard to conditions and related information about life choice implications (SHA, 2005)
- Information about living wills in the case of serious health conditions, and about advance statements and access to advocacy in the case of people with mental health problems (SHA, 2005; Mental Health (Care and Treatment) (Scotland) Act, 2003)
- Information for carers about their rights and options for help, as well as about specific health conditions and implications for the service user and family members, and information about carers benefits and entitlements (TPAS, 1998; SHA, 2005)
- Information about current research in regard to serious health issues (SHA, 2005)
- Information about how to complain about the service and
- Information about how to gain access to independent advocacy (Scottish Executive guidance, 2006).

6.5.   The Social Exclusion Unit (2005a) explicitly addressed issues of awareness of service provision. It highlighted that there is no 'one size fits all' formula for effective provision of information and communication for disadvantaged groups, and that different approaches can benefit different people. While issuing a caution regarding the lack of robust evaluation evidence about the success of different approaches to information and communication with disadvantaged people, the report identified some key principles of best practice:

- Getting the basics right – making information easier to understand so that everyone using public services benefits
- Understanding customers – involving people and working with partners to get effective and efficient results
- Using new technologies and outreach – either to complement or to provide an alternative to text-based products (Social Exclusion Unit, 2005a, p40).

6.6.   The literature points to the need for written information to be easy to understand and written in plain English. Principles "include the use of short sentences, simple punctuation and everyday language" (Social Exclusion Unit, 2005a) along with an understanding of what people need and of where people access information from.

6.7.   The following case example demonstrates the benefits of comprehensive information being available.

Information on services for people with learning disabilities – East Renfrewshire
The Enable family advice service in East Renfrewshire is a local independent service, funded by East Renfrewshire social work department and managed by Enable. It offers clear, accurate, independent information on anything which affects people with learning disabilities and their families in the East Renfrewshire area. It is linked to, and backed by, Enable's national information service but can offer the ongoing face-to-face support and knowledge of local networks and services that individuals and families need. (Scottish Executive, 2000, p31.

6.8.   One co-ordinated approach in promoting preventative advice for young people using some of the approaches employed in community development is highlighted below.

Youth Education Project – co-ordinated, preventative advice for young people
A pilot Youth Education Project started in April 2002 and was developed by a partnership of homelessness and related services including: East Dunbartonshire Council homelessness staff, Social Work Through Care and 3 local secondary schools. The project built on SCSH's training pack 'I'm Offski'. SCSH's Education Worker worked with local young people to produce a booklet on 'housing options' for young people. In parallel Project 101, a participatory youth advice and development service, collaborated with Tenant Participation officers and the Homelessness Team to deliver housing and homelessness awareness sessions to 160 pupils. The joint team produced high quality presentations on the local housing system, on housing options, on processes of applying for housing across sectors, on homelessness and related options and on tenant participation. This initiative was subsequently extended. (Rosengard Associates, 2003)

6.9.   In some cases, services have sought to make more information available about their services through direct marketing, often aimed at groups who have been found particularly 'hard to reach'. The following example illustrates how learndirect sought to increase take up of services.

Improving awareness and take-up among people from ethnic minorities – learndirect
learndirect is the largest publicly-funded online learning provider in the UK. Aiming to improve take-up rates by Bangladeshi and Pakistani people with low levels of English fluency and literacy, it advertised the service on Asian TV and radio and in the Asian press. Additionally, an advice line was provided in the relevant languages and this was promoted through community outreach. The service was also made available in Somali.

It was found that different types of media were found to be effective for different groups (Social Exclusion Unit, 2005a: p52)

IMPROVING ACCESS THROUGH CREATIVE TARGETING AND FLEXIBILITY

6.10.   As reported in Chapter Three, the literature identifies organisational and structural barriers to accessing services, and these barriers operate whether or not people know of their existence. Best practice in overcoming the most commonly identified constraints is discussed below.

6.11.   One prevalent constraint is that of waiting times to access services and the problems of inflexible services were identified in Chapters Three and Four, where it was clear that access arrangements are not generally convenient for people. Moreover, problems of access are particularly acute at times of crisis, which can often occur outside normal opening hours.

6.12.   Increasingly it is argued therefore that single service access points that are accessible in relation to time and place should be provided.

> *"People with complex care needs require a single point of contact to mobilise support if there is an unexpected change in their needs or a failure in agreed service provision. Further work needs to be done to establish how this can be achieved on a 24/7 basis by, for example, linking case management with out-of-hours* (Department of Health, 2006a, p116).

6.13.   The Audit Commission (2002b) has identified long waiting lists for drug problem services as a national problem that has arisen due to the inadequate expansion in services in the face of increasing drug problems. This gap is exacerbated by inefficient bureaucracy and inflexible treatment regimes. The report concluded that:

> *"For the most part, an incremental approach to change, concentrating first on key blockages, such as long waiting times, is likely to be the best way forward" (Audit Commission, 2002b, p74).*

6.14.   Two examples of flexible service responses to needs are illustrated below.

Adult learning – Granby Island
Granby Island, an adult learning community organisation in Plymouth, adopts a flexible approach to delivering education courses. It argues that its courses are more likely to engage people than those run by the local further education college, which are only available at set times and require a minimum number of people to attend.

Two year funding enabled Granby Island to provide courses for local residents who wanted the flexibility to learn at different times during the week. By employing 2 full-time staff, Granby Island provided learners with the opportunities to learn at any time of the week, to receive more one to one support, and to participate in some small classes (less than 10 people, which is the minimum required by statutory providers). While the funding was intended for the provision of set courses, Granby Island was able to use it creatively to promote access, and to improve the service in order to sustain participation. Basically it enabled extra support for learners – including staff outreach work to go and collect learners, help with childcare, follow up issues with people and contact people if they do not turn up (Social Exclusion Unit, 2005, p110).

Glasgow City Council Sign Language Interpreter Service (SLIS)
This is an innovative initiative for deaf, hearing impaired and deafblind people, who often experience extreme difficulties in communication and accessing information. Deaf people often require an interpreter in their personal communications, for example in relation to medical problems, or a job interview. As there is a huge shortage of qualified interpreters the system aims for effective use of limited resources.

A website has been developed containing essential information about the SLIS, with the key element being an on-line booking service. This gives the client easy, 24-hour access to booking the services of a sign language interpreter. The initiative was formally launched in November 2002 and in the month leading up to the launch over 200 clients signed up. (Scottish Executive, 2003a, p45).

6.15.   While some people prefer not to use computer-based services, others find them useful, particularly if they are trained in their use. In relation to the constraints on access highlighted in Chapter Three, there is evidence that advantages can accrue for people who find it difficult to get to services because of disability, or because of rurality and distance from major centres. An example from the Modernising Government Fund Progress Report Round One (Scottish Executive, 2003 a, b, c) illustrates how use of new technologies can facilitate access to services, including for people with multiple and complex needs.

Aberdeenshire Council– Teaching Internet Use
6.16.   Many older people are not familiar with IT, have additional needs related to disabilities, and may be excluded from established education resources. However, some services have specifically targeted their needs.

'What's IT all about' project
This project provides a free introduction and continued teaching in IT and the internet for people over 50.

"A recurring comment from individuals enquiring about the project was that due to a disability, such as loss of hearing or arthritis, community group classes were impossible to join. To overcome this 25 people in the area are now visited by volunteers and find that individual attention in their own homes has transformed their ability to grasp computing. There are 5 Sheltered Housing schemes involved, where small groups of residents enjoy weekly visits from a volunteer, but also now have the computer facilities on-site to practice between lessons." (Scottish Executive, 2003a, p.38)

IMPROVING THE EXPERIENCE OF SERVICE PROVISION

Addressing whole person needs

6.17.   Good practice guidance stresses the case for comprehensive needs assessments that considers the 'whole person' (Scottish Executive, 2001a; Rankin and Regan, 2004; Morris, 1999). Addressing needs holistically includes, for example, addressing needs for employment or meaningful occupation (see for example: SACDAM/SACAM, 2003; Social Exclusion Unit, 2004a; Rankin and Regan, 2004; Department of Health, 2005a; Turning Point, 2005). Additionally, services should be designed around people's needs rather than them being "forced to fit around the service already provided" (Department of Health, 2006a).

6.18.   An example of a service that addresses needs holistically is shown below.

The Matrix, South Tyneside
The Matrix in South Tyneside is a positive example of a complex needs service for young people. Co-located under one roof is a network of key providers, including a drugs action team worker, an arrest referral worker, representatives from both health and housing authorities, a mental health nurse and a link to Connexions. There is a common assessment procedure and the team makes collective decisions about which worker is most appropriate to work with a particular client. Although setting up this one stop shop was not without challenges, group training and regular team meetings have helped staff at the Matrix to negotiate potential problems of different professional working practices. (Rankin and Regan, 2004, p67)

6.19.   The need for sensitive approaches by services that address the whole needs is demonstrated for people with learning disabilities, as discussed below.

Addressing self-harm
A study that focused on self-harm amongst people with learning disabilities stressed the need for problem awareness and sensitivity, as well as a personalised, empowering approach (James and Warner, 2005). It found that self-harm among women with learning disabilities, is in fact a way of exerting control and coping, just as it is for others in the community who self harm. Considering the harmful impact of institutionalized, restrictive regimes on women with learning disabilities and complex needs, the authors suggest that the control exerted by the treatment regime may increase self-harm. Good practice identified included the need to involve women with learning disabilities as much as possible in planning, implementing and reviewing their treatment. One option may be 'a living will' which can be negotiated when someone is well enough to have a say over their treatment at times of crisis. The authors comment, "If we fail to recognize that such women actively engage with their own lives we build services that treat such women as passive and increase the ways in which they are controlled…This means understanding them in the context of their whole lives" (p 126).

6.20.   In sum, 'whole person' assessments require a strategic approach that:

- Takes a longer-term perspective
- Makes every effort to take on board the views of service users and carers
- Is sensitive to particular needs
- Takes the time needed for effective dialogue with the service user and agencies
- Trains staff beyond singular professional visions to encompass a range of needs
- Reviews the process and outcomes over time. (Keene, 2001; Rankin and Regan, 2004; Baron, 2005; Humphrey et al, 2005; Noel et al, 2005).

Advantages of single entry points to services

6.21.   In seeking to address the problems of service fragmentation highlighted in previous chapters, the concept of single access points or 'one stop' shops is increasingly being advocated. Here people can access a number of services either under one roof or by means of a single phone call, so making it easier for people to:

- Find out about available services and
- Access appropriate services to meet different needs (see for example, Scottish Executive, 2003a; Rankin and Regan, 2004; and The Social Exclusion Unit, 2005a and b.)

6.22.   Such approaches can help to address a number of problems identified in the literature:

- Inappropriate service referrals (Social Exclusion Unit, 2004; George, 2000a)
- One or more problems getting lost in the referral process (Humphreys, 2005)
- People accessing services that only deal with one part of their needs (Keene, 2001)
- People being excluded from services because of additional problems, for example mental health or addiction issues excluding people from services for domestic violence (Humphreys, 2005)
- Difficulties in accessing services because of remoteness from them.

> **'One stop' approaches**
> Some Scottish 'one stop' examples involve a number of council services being co-located in a single building as in Moray and South Lanarkshire Council areas (Scottish Executive, 2003a). Others are multi-agency, such as the Homelessness Access Point in Edinburgh which involves Health, Social Work, benefits advice and voluntary sector services (Rosengard et al, 2003); and the one stop partnership health services for homeless people in Glasgow[6] and Newcastle[7], and for asylum seekers in Glasgow[8].

6.23.   The single access point model for help and support is further developed by the model of the Connected Care Centre (as advocated by Turning Points). As highlighted in Chapters Four and Five, people living in the poorest neighbourhoods with the greatest needs are often the least likely to have access to the services and support which would help them improve their lives and life chances. Connected Care is a pilot programme that aims to tackle this.

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[6] The Glasgow partnership health centre (Hunter Street Homeless Health and Social Care Centre) was opened on 05/04/2004 (www.scotland.gov.uk. Newsreleases/2004/04/5347)
[7] The Joseph Cowan Healthcare centre is provided via a partnership between the 3Ns Mental Health NHS Trust and Byker Street Housing Association (see: North Tyneside Council (2005) *Looking for Somewhere to Stay: Accommodation Guide.*
[8] www.scottishrefugeecouncil.org.uk

> **Connected Care in Hartlepool**
> The Connected Care centre is being developed through a partnership between Turning Point, a charity providing services for people with complex needs, Hartlepool PCT, the local authority and a range of community groups, involving the local community in the design and delivery of services. The Director of Primary Care Development and Modernisation at Hartlepool PCT described how a recently completed audit gave the Connected Care partners insights into how better connected services could improve the lives of those in the greatest need.
>
> "For instance, someone with substance issues or learning difficulties would often get a raw deal in the past because they wouldn't know how to navigate through the system. Connected Care workers will be trained to understand what the different organisations offer because if someone comes to them with housing issues they may also have problems with debt and with their health. Historically, they usually get one part of their problem dealt with or looked after but they tend to get pushed from pillar to post. This way they should see someone who has an overview of the whole system and can help with all their needs and complex issues" (Department of Health, 2006a, p169).

6.24.   Further information on the Connected Care centre model is given in Appendix 3 along with details of a single access service point involving the use of technology in Argyll and Bute, and another in Torry, a deprived area in Aberdeen.

Outreach services

6.25.   As noted in Chapter Four, some people find it difficult to engage with services for various reasons. An alternative and/or complementary model to centre based services is of outreach services that actively seek out clients, rather than waiting until existing or potential clients find them. Many studies have identified active outreach as services that work well, and particularly so for clients who find it difficult to access services or whom service providers have described as 'hard to reach' (Edwards, 2003; Crisis, 2005; Rankin and Regan, 2004; Social Exclusion Unit, 2005a). The Social Exclusion Unit (2005a) defines outreach in the following way:

> *"We are using the term outreach to mean the provision of information about and support to engage with services in a way that is most convenient for the individual. It helps to build trust and provides support and encouragement to overcome the barriers that people may face in taking up services"* (p54).

6.26.   The Social Exclusion Unit found that the use of outreach has increased, with almost one in 3 survey respondents stating that they carried out some kind of community outreach in relation to the 3 disadvantaged groups who comprised the focus of the study. The biggest increase in the use of outreach had taken place in the statutory sector. Nevertheless, the report cautioned that outreach is resource intensive and is often subject to short term funding. This was also highlighted in Chapter Four in relation to Sure Start services in Scotland, while pro-active outreach has also been a central and broadly successful method of the Rough Sleepers Initiative in Scotland and UK-wide (Randall and Brown, 2002; Fitzpatrick et al, 2005; Reid and Howie, 2004). Fitzpatrick et al quote one homeless woman who wanted to

access supported accommodation, who said, "But I couldn't be without my outreach worker. If it wasn't for her, you ken, I'd probably still be out on the street" (2005, p88).

6.27. In relation to Sure Start south of the border, the Department for Education and Sciences (DfES) has issued new practice guidance to refocus the activities within children's centres, to ensure they collect data and information on the most excluded families and place greater emphasis on outreach and home visits to support these families. [9]

Tackling cultural barriers – Sure Start Barkerend
Barkerend Sure Start in Bradford is using outreach techniques to tackle cultural barriers that can make it hard for Muslim people to access their services. When notified about a newborn baby, an outreach worker makes contact in order to gain the trust of the family and to assess whether they might benefit from Sure Start help. The outreach worker talks in depth with the new mother, focusing on her needs and interests, and then encourages her to come into the Sure Start Centre.

The aim is not just to get people into the Sure Start Centre but to help them access other services too. Outreach workers may accompany people to hospital appointments, for example. Sure Start also brings college tutors into the Centre so that the new mothers get to know them in 'friendly' territory. (Social Exclusion Unit, 2005a, p56)

6.28. The need for active outreach services to be culturally sensitive is further demonstrated in the following example of a service in Tower Hamlets.

Family Support workers - Tower Hamlets
Given the problems faced by minority ethnic households in accessing the services they require, one study in Tower Hamlets highlighted that achieving appropriate responses for families was helped by a team of Family Support Workers who worked practically and regularly with families, and who were alert to the onset of potential crises and could take preventative action. The Family Support Worker was able to advise, explain, contact and escort families to other secondary services.

A match of cultures between worker and service-user was said to provide shared aims and goals, broke through language barriers for non-English speakers and established mutuality of feeling in so far as a shared culture solidified interpersonal relationships. Workers, all of whom were women, were often from the same community.
Ethnicity and gender cemented staff-user relationships, helping to inform interventions that were sensitive to the cultural beliefs and views of the family. The role of trust was significant, particularly as service users had felt insecure about involvement with other social and health service professionals, due to child protection issues. Service users referred to being listened to by the Family Support Workers.

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[9] Reported by Mark Gould: "Unsure Future". In *Society Guardian*, The Guardian May 24 2006

> Another dimension of the Family Support Worker's role was that of advocate. They were able to listen to and understand the family's point of view and communicate the family's specific health and social care needs to other agencies – whether social services, benefits, counselling services or local/national action groups (Gray, 2003).

Developing care or pathways plans

6.29.   Good practice guidelines in community care stress the need for support to be delivered following comprehensive needs assessments, with the development of a care plan or care pathway that clearly sets out the services people need, and how and by whom they will be delivered (Scottish Executive, 2004 a and b). However the shortfalls of care planning were highlighted in Chapter Four, and it has been argued that "the process is now largely restricted to those on the cusp of institutional care" (Hudson et al, 2004).

6.30.   Nevertheless, the benefits of systematic care planning are clearly evident, as the experience of some voluntary sector organisations shows.

> **Joint planning between support workers and people requiring support**
> Maggie has a folder… that is used to structure her support. The ideas in the folder range from every day issues about medication and food to more general themes that include life goals, education, employment and values. With this method of care planning, items in the folder can be taken out or replaced when the person being supported, along with their support worker, decide to do so. This allows for the plan to be flexible and adapt as the lives of the individuals concerned change (DEMOS, 2005, p13).

NEGOTIATING FRAGMENTED SERVICES

The need for link and co-ordination roles

6.31.   Given that service fragmentation and its impacts cannot be resolved overnight, one corrective model developed by health and social care services is that of a 'service navigator' or link worker (Rankin and Regan, 2004; Turning Point, 2005). Such link roles have varied purposes and their common features are that they address multiple issues, cross service boundaries, promote and co-ordinate access and support, and aim to include those who are 'hard to reach'.

6.32.   The role of link worker draws on the experience of implementing care management in the 1990s following the policy shift from institutional to community care, with its emphasis on user and carer empowerment and individually tailored services based on assessment need and the coordination of care across agency boundaries (Halliday & Asthana, 2004).

Link workers and service navigators

The proposed 'service navigator' would be expected to know about all mainstream and specialist services, as well as to appreciate the range of presenting problems and their interconnections – e.g. particular needs, housing, benefits and employment law, cultural impacts, offending and homelessness issues. They would also engage in advocacy and brokerage across roles and agencies (Rankin and Regan, 2004).

The Mind the Gaps report stresses the value of link workers who 'stay with' the client, especially the more chaotic individuals, in their early contacts with the service. They identify successful alcohol liaison nurse models, applied particularly in Edinburgh, which could be adapted (SACDM & SACAM, 2003, p67).

Other types of linking pin roles found invaluable have been those co-ordinating complex inter-agency developments, such as hospital or hostel reprovisioning, where outcomes are dependent on liaison with a very wide range of housing and support providers. One example mentioned in this study was the role of HomeLink in Glasgow in obtaining community-based alternatives to hospital care (Petch et al, 2000).

An initiative from Cornwall and the Isles of Scilly, involving strategic and operational change across health and social care boundaries in order to provide coordinated assessment and care for children with complex needs and their families, has introduced link workers (Halliday & Asthana, 2004). The link workers act as central, key contacts for families and professionals alike.

6.33.   Another regularly referred to example of link work was developed by the Revolving Doors Agency that works with offenders who have multiple needs.

Revolving Doors Agency Link Worker

This voluntary organisation provides an innovative approach to meeting the needs of ex-offenders, and offers an example of how a service navigator would function.

Link Workers were established in 4 London boroughs and in Buckinghamshire in 2000, with the aim of providing whole needs support to prevent offenders from going on a continual journey through the revolving door to prison.

Concentrating on those who are typically hard to reach by services, the scheme targeted clients with mental health problems, drug dependency, homelessness and poor housing. They offered clients help with making benefit claims, access to health services, assistance with accommodation, as well as general advocacy and emotional support.
In addition to providing a navigational role, Link Workers worked in teams and operated on the principle that there were no closed cases. Twenty four per cent of clients were deemed to experience 'improvement' in their lives with the benefit of a Link Worker, and none saw their situation get any worse. (Moran and O'Shea, 2003, Revolving Doors Agency 2003), quoted in Rankin and Regan, 2004, p 65.)

6.34.   Evidence of the need to counteract fragmentation and link across services stretches beyond the UK, and one Australian study found that,

> *"Most effective interventions involved scenarios where there were links between the different programs being accessed by the individual, and collaboration among service workers. Clear boundaries and structures for the individual were also identified as effective"* (Department of Human Services, 2003, p4)

6.35.   The introduction of such workers has workforce development implications as "it is not evident that individuals with such qualities are readily available" (Hudson et al, 2004). Additionally, Keene (2001) sees the need for the development of a new type of professional who would specialise in clients with complex needs.

6.36.   There is clearly some overlap between link roles and aspects of care co-ordination, as was noted in Chapter Four. New bridging roles are being created, such as the 'community matron', a model favoured by the Department of Health (2006a).

> *"Community matrons are case managers with advanced level clinical skills and expertise in dealing with patients with complex long-term conditions and high intensity needs. This is a clinical role with responsibility for planning, managing, delivering and co-ordinating care for patients with highly complex needs living in their own homes and communities" (p.218).*

6.37.   Such new health service roles are however criticised from a social model perspective. It is argued that the new community matron will fail to recognise:

> *"...the reasons why the health of people with long term conditions may deteriorate enough to result in hospital admission are more to do with socioeconomic, cultural, psychological and community factors than healthcare" (Hudson, 2005, p383).*

6.38.   Hudson also questions whether community matrons should or could carry out effective case management for people with physical and learning difficulties, for example, where there has long been a tradition of a social rather than a medical model of care. In a similar vein, Hunter (2005) had this to say of the Department of Health paper on supporting people with long term conditions:

> *"The 5 chapters, 3 annexes and 48 pages contain no mention of direct payments, and no reference to transport, housing benefits or employment. None of its good practice examples focus on social work, and people with long-term conditions are referred to as patients throughout. But the most obvious snub to social workers is the introduction of community matrons. Despite the wealth of experience among social workers who have case management roles, only those with a nursing qualification will be eligible for the new role" (Hunter, 2005, quoted in Hudson 2005, p383).*

Information sharing to prevent service users having to repeat their stories

6.39.   Single shared assessments, whereby all relevant services are involved in a joint process of assessing need, are designed both to improve inter-service co-ordination and to prevent service users having to repeat the same information, often of a sensitive or personal nature. These assessments were introduced initially for elderly people, and are now being rolled out across other community care groups, including people with multiple and/or complex needs (Scottish Executive, 2004a).

6.40.   To allow agencies to share data and to improve people's pathway or journey through services, new IT was developed and the resultant 'E-Care' plays a major role in the New Future's Agenda in Scotland. The links between information sharing, E-Care and Single Shared Assessments are described in more detail below.

> **E-Care, single shared assessments and information sharing systems**
> E-Care was developed as a major part of the Joint Futures Agenda and the Scottish Executive's Modernising Fund Projects, which were set up to improve the quality and comparability of the information available to support the delivery of services, to promote information sharing to improve service co-ordination and integration, and to prevent service users being faced with repeat requests for information. However, "Information sharing can only work properly if the data definitions and data sets used to record the information are standardised, and technology gives professionals quick, easy secure access to that shared information" (Scottish Executive, 2003a, p11).

6.41.   Today there are increasing examples of 'E-Care'; some are listed below and others are outlined in Appendix Three:

- Services for older people with mental health problems and the use of Single Shared Assessment by NHS Lanarkshire along with North and South Lanarkshire Councils
- Joint equipment stores, such as in the Borders and Lothian
- Borders Police Information Networking for Family Protections Officers that gives the facility to share information already in several existing policing systems thus minimising data fragments as well as data entry and administration.

Joining up services

6.42.   Holistic, co-ordinated and flexible approaches aim to counteract the impact of bureaucracy and fragmentation. The Modernising Government Report emphasises that such approaches need to be supported by 4 main components: technical, organisational, cultural and a framework for information sharing.

- Technical aspects include integrated technology and technical arrangements, "such as an integrated telecommunications infrastructure and interoperability"
- Organisational conditions include corporate and integrated organisational structures and arrangements and a corporate approach to information management

- Positive organisational and service cultures are also key to promoting integration and joint work and require "strong leadership in driving through the changes that join up services across organisational boundaries"
- Protocols must enable information sharing, control data sharing and protect privacy.

"There is also a need to deal with the important concerns over data protection, to ensure that alongside the drive to join up services and to share information there are strong controls that protect the privacy of the individual and the access to personal data" (Scottish Executive, 2003a, p3).
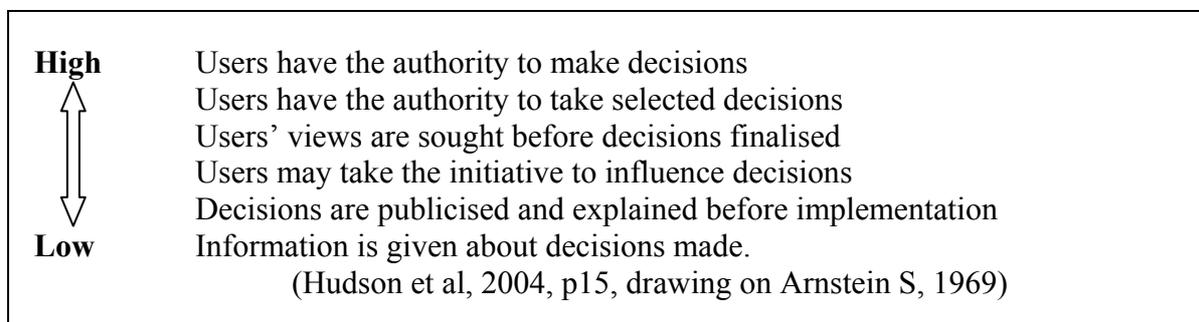

INCREASING SERVICE USER INVOLVEMENT AND CONTROL

6.43.   The literature highlights the need to work with service users in both the development and delivery of services (Turning Point, 2005; Rankin and Regan, 2004; Edwards, 2003; Leadbeater, 2004 and The Social Exclusion Unit, 2005a and b). As noted above, Turning Point (2005) advocate that at the point of development of Connected Care Centres, community audits should be carried out to ascertain the services that are most needed.

6.44.   Much of the discussion on service user involvement in the literature on support and care relates to how best to involve individual service users to improve outcomes. Leadbeater (2004) for example, has outlined 'a few simple rules' that can help services to have a positive impact. All these rules involve the service user closely in planning their own pathway. In relevant cases, carers should also be involved.

- Set incremental goals, starting small and manageably
- Specify clearly what the user and the service professionals expect to do
- Keep joint records of achievement and performance to reinforce success
- Give users a mix of options through which they can achieve their goals
- Frame the policy in an aspirational way to excite ambition
- Provide role models and peer-to-peer support to build confidence.

6.45.   Service user involvement may take place at a number of different levels. Hudson et al (2004) draw on Arnstein's long referred to 'ladder of participation' as shown below.

High	Users have the authority to make decisions
⬆	Users have the authority to take selected decisions
⬍	Users' views are sought before decisions finalised
⬍	Users may take the initiative to influence decisions
⬇	Decisions are publicised and explained before implementation
Low	Information is given about decisions made.
	(Hudson et al, 2004, p15, drawing on Arnstein S, 1969)

6.46.   Rather than simply focus on levels of participation it is important to recognise that promoting and sustaining participation in practice requires a range of approaches and methods, as well as an appreciation of the factors and structures influencing participation. Davidson represented this in the form of a wheel of empowerment (Davidson, 1998).

6.47.   Notwithstanding these different levels of involvement, there is a broad consensus in the literature that effective and responsive services need to ensure increased service user, and where appropriate, carer, involvement. One recent initiative to promote the involvement of people in their healthcare is the Expert Patients Programme (see Appendix 3).

Choice and enabling service users and carers to be co producers of their care

6.48.   To enable user empowerment it is argued that service users must be seen as co-producers of their care (Claire and Cox, 2003; Rankin and Regan, 2004; Leadbeater, 2004; DEMOS, 2005; Turning Point, 2005; Scottish Executive, 2006b).

6.49.   The following describes initiatives in the field of learning disabilities that allow for greater involvement in the planning and provision of care.

The 'In Control' approach
This enables social care budgets for individual clients to be disaggregated, and an annual budget to be allocated directly to the families for use in creating the best care packages. They can choose which support workers to employ and what hours they should work. They can also use the money flexibly to spend on treats, outings, different modes of transport, and technology at home. First, however, there is usually an intensive process of consultation between the client, their family, and social workers, in order to draw up a care plan centred on the person, their needs and aspirations. This is the basis for organising both formal and informal care.   The families involved in the In Control pilots found that planning has to be collaborative, very down to earth and colloquial and is never a one off. Plans have to be adjusted and adopted, and as people change, they grow in confidence or their needs change. By aiding people to review their care package and to identify the care package they would like, this gives them a voice in shaping their care. However, having a say requires some choice in relation to services. One mother on the In Control programme said, "I can make 10 pounds go a lot further than the local authority." (DEMOS 2005, p28).

Providing flexible person centred care for people with learning disabilities
Inclusion Glasgow's packages of care include a one-off resource to support people immediately after they leave hospital. The organisation place the agreed funding for the person in a bank account, known as the service fund. How the fund is managed and used is decided in the person's plan. They can spend it on care at home, in work, or for leisure pursuits. Out of 28 people who used to be in Lennox Castle, all have their own home, 7 own them and some have jobs. None has returned to hospital. As planned, natural supports and networks play a more significant part in the overall pattern of support, and the cost of the care package should reduce (Scottish Executive 2000, p41).

User purchasing systems

Direct Payments

6.50.   Support for the principle of direct payments through legislation (i.e. Community Care (Direct Payments) Act 1996 and the Health and Social Care Act, 2001), alongside evidence of the positive difference direct payments can make to people's lives by providing the flexibility and control that service users seek, has not translated into the transformation expected (Leece and Bornat, 2006; Witcher et al, 2000). Additionally we have seen that for various reasons there has been a lower take-up in Scotland (Pearson, 2006) and that take up has been relatively low amongst people with mental health problems (Ridley, 2006).

6.51.   Recent research on direct payments for mental health service users in Scotland points to the obstacles of misunderstandings about eligibility; lack of person centred approaches in community care assessments; perceived threats to the funding of services; concerns about people's ability to manage, especially if they experience fluctuating health problems; and a lack of adequate support organisations (Ridley, 2006). There is therefore a need for targeted information and education to counteract the obstacles of low awareness, lack of understanding and concerns about the impact of direct payments on service users and professionals such as care managers. Advocacy support is also required to encourage those eligible to take up these payments.

6.52.   The literature overall emphasises the advantages to be gained from direct payments for those who take them up as well as for service providers.

> *"A significant feature has been how the quality of life of the disabled person has improved: the sense of feeling in control has been a central aspect in all the findings…choice and flexibility were the other themes. The other significant point is cost effectiveness compared with in-house direct service provision"* (quoted in Hudson et al, 2004, p27).

6.53.   Direct payments and Independent Living Fund Options should be systematically offered as an option by care managers when doing community care assessments, as legislation now makes direct payments mandatory not discretionary. From another perspective, it has been pointed out that direct payments may cause conflicts and tensions with "the development of strategic, whole systems approaches to local service commissioning" (Hudson et al, 2004, p28). In Canada and the USA, the shift towards individualised planning and funding options has been understood more positively as a "move from service and placement towards capacity building and participation" (Hutchison et al, 2006).

Access to Advocacy

6.54.   The need for advocacy has been highlighted in the literature and policy documents across various client groups including: learning disability (Scottish Executive, 2000,); mental health (Ridley and Jones, 2002), people with co-occurring substance use problems and mental health problems (SACDM and SACAM 2003) disadvantaged people and those with complex needs (Scottish Exclusion Unit, 2005a; Rankin and Regan, 2004; DEMOS 2005).

6.55.   The Mental Health (Care and Treatment) (Scotland) Act 2003 gives a right to access advocacy to people suffering from mental illness, dementia, learning disability, autism, brain injury/damage, or personality disorder. Other people can access advocacy services, but do not have a legal right.

6.56.   The benefit of advocacy is shown by the case of one young woman. She had been brought up by foster parents and is now at university. When she was 13, she got in touch with *Who Cares Scotland,* which helps young people in care to have their voices heard.

> *"Without Who Cares services may have been ill-coordinated and Ann's voice may have been drowned out. Ann is not just a client of social work services she has become a participant, contributor and investor, of her own time and effort" (DEMOS, 2005, p15).*

6.57.   While national and local policy makers have taken the need for advocacy on board and more funding has been channelled into advocacy, it will be important to monitor its local availability for equity reasons and to ensure that policy is translated into practice.

6.58.   Additionally, it is important to recognise that people with a legal entitlement to advocacy may present to services via homelessness services or refugee services. Access to advocacy should be considered in respect of multiple service points.

6.59.   For some people, peer advocacy has been found to be particularly effective, as shown below.

Bristol and South Gloucestershire People First – 'Side by side' peer advocacy
This peer advocacy service was set up by People First because people with learning difficulties felt unable to access local advocacy services. One of the benefits of people with learning difficulties providing the support is their insight into what their peers actually want from an advocate: "If people don't feel in control with the support they've got it's not good support."

People with learning difficulties are also learning new skills and becoming 'experts' themselves, rather than depending on traditional services. Successes have included resolving a bullying complaint, helping members to gain more control of their money and medication, and making medication forms more accessible after the issue was raised (Social Exclusion Unit, 2005a, p90).

Community development, collective empowerment and partnerships

6.60.   There has been more attention paid in the literature and guidance to service user participation at the individual level, rather than to participation as collective consumers or citizens. To promote collective rights and empowerment there needs to be attention to community development, collective advocacy approaches, and their links with social inclusion. Essentially such approaches require a partnership perspective to inform the ways in which professionals relate to service users (Barr et al, 2001; Henderson, 2005).

> **Community development**
>
> Four action research projects were established ranging from the promotion of a caring community through citizen participation and worker collaboration (Fife); empowerment and service improvement for excluded carers (Glasgow); achieving full citizenship for disabled people (South Lanarkshire) and reaching, supporting and promoting the voice of care users in remote communities (Lochaber). Barr et al (2001) stress the need for "a more holistic approach whereby community care is located within a broader focus of community concerns".
>
> Additionally, collective empowerment requires:
>
> - skilled staff to help build the capacity of the voluntary sector
>
> - more emphasis on accessibility and contact between frontline staff, service users and community organisations, "particularly in social work departments"
>
> - "localisation and participatory principles"
>
> - "openness to joint working by social work and voluntary sector staff"
>
> - changed staff attitudes – "staff now value the opinions of local people".

6.61.   While most community development focuses on empowering local residents to clarify and articulate their collective views on local needs and services, the same aims are relevant to people with multiple and complex needs as service users.

> **Collective advocacy**
>
> There are an increasing number of examples of collective advocacy in Scotland. One innovative form of service user representation is the multi-agency partnership in Glasgow for young people in and leaving care – The Big Step. This both involves extensive user representation of young people in and leaving care in its management and serves as a vehicle through which young people's views can be systematically and directly heard by service providers (Rosengard and Jackson, 2005).
>
> To support refugee settlement, Refugee Community Organisations enable groups of refugees to work together to tackle problems promoted through the Scottish and English Refugee Councils. This approach is critical to integration (Wren et al, 2004). Focusing on the role of housing providers in supporting and linking with RCO's, Perry (2005) reports that South London Housing Association appointed a link worker for one year to work with an RCO with which it was building a relationship.

6.62.   One example of collective user involvement with positive outcomes focused on people with learning disabilities through a Best Value review. The same approach, however, could be relevant to other client groups.

Collective involvement in service redesign

Learning Disability Services Re-design – South Lanarkshire
In 1997, South Lanarkshire embarked on Best Value Reviews of residential and day services for people with learning disabilities, and at the same time looked at facilities for respite and assessment and care management resources. The Best Value Review fully involved service users and their carers in an examination of current services, their outcomes and issues. Critical issues were the many varied health matters which arose for service users, transport provision, carers views in relation to the nature of the service provided, and respite services which needed to be expanded.

Following extensive user and carer involvement, outcomes included:

- Redesign of activities and day services
- Staff employed in community support teams to support people on a local area co-ordination model
- Capital investment in the redesign of 3 locations to provide integrated community centre models that can be used flexibly during the day and in the evening, both by people with learning disabilities and the community
- Providing employment opportunities for people with learning disabilities
- Developing respite services in purpose built facilities

The activity which has taken place has been multi disciplinary and multi agency with a focus on information, assessment and care management review, advocacy and community development (Community Care Works: Database of Good Practise in Community Care, University of Glasgow).

Hostel reprovisioning in Glasgow
The Glasgow Homelessness Partnership were finalists for outstanding achievement in social housing in Scotland for a Chartered Institute of Housing award in November 2004. The partnership was nominated for the training programme it has implemented with Glasgow Simon Community's Resettlement Service. The aim of this venture is to increase the appreciation of professionals of the service user perspective. This has involved service user members of the Simon Community in making a series of presentations to staff from a range of agencies and services about their experiences of homelessness, and their views on the service responses that they received. Most recently, this input is being extended to administrative and reception staff. Some of the service users involved in this training programme had already been 'peer educators' who were supported by the resettlement training service to provide resettlement training to other hostel residents (Glasgow Simon Community newsletters[10], www.glasgowsimon.org).

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[10] Glasgow Simon Community supplied information to the research team on the training programme.

> **Glasgow Homeless Network (GHN)** produced a report, 'Where will they go?' in 2003, for the Homelessness Partnership. This outlined homeless people's opinions of homelessness, hostels and homelessness services in the city. The report was based on systematic consultation with homeless people and hostel residents to ensure that their views were heard and taken into account in the hostel de-commissioning and re-provisioning process. GHN subsequently established a Service User Involvement project to engage service users who want to get involved in homelessness planning or services (Glasgow Homeless Network[11]).

6.63.   A community development approach, working in partnership is further illustrated by another recent initiative in Glasgow.

> **Homelessness prevention through community-based education in partnership**
> Glasgow Simon Community's Resettlement Team is working on a pilot project with Greater Easterhouse Money Advice Project (GEMAP) to develop community-based training that will involve volunteer service users as peer educators.
>
> The programme aims to develop awareness around debt management and housing information and advice. The peer educators have all experienced difficulties with money management or housing issues (in most cases both), and will be trained to design and deliver their own sessions for this workshop programme. The workshops will explore situations that could lead to housing or financial difficulties and build participants' confidence to deal with difficult situations and to access appropriate support agencies within their community. The approach of peer education has recently attracted the active interest of SAFIR, a Norwegian group based in Oslo. This stemmed from an initial fact-finding visit by SAFIR and resulted in an exchange visit (Simon Community unpublished report, July 2006[12]).

6.64.   Drawing on these examples and the wider literature, enabling conditions for promoting collective empowerment at policy level include:

- Ensuring that people with multiple and complex needs are treated as citizens with rights of self-determination and participation, and with a contribution to make
- Policies and practice built on the 'social model'
- Active promotion and support (capacity building) for empowerment through proper resourcing of sustainable mechanisms for collective participation. (Barr et al, 2001; Wren et al, 2004; Morris, 2005; Hudson, 2005)

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[11] www.ghn.org.uk

[12] www.glasgowsimon.org. Note Simon Community submitted report to research team

ENSURING SMOOTH TRANSITIONS

6.65. Bureaucracy and fragmentation mitigate against straightforward and positive transitions, whether these are caused by changes in age or in circumstances, such as leaving institutions or hostels. Unmet needs arise not only because of service gaps, but also because of existing services' client criteria. People with multiple and complex needs may fall between the criteria employed by child and adult services, or mental health and criminal justice services, or housing and support services, for example (Social Exclusion Unit, 2005b).

6.66. The following example highlights the benefits to be gained through accessible, flexible and co-located service arrangements to facilitate continuity of support.

> **West Euston One-Stop-Shop**
> In this partnership one-stop-shop service people can walk in to gain advice; access services; use the computers, internet and library. Within the partnership, the Connexions service (dealing with young people with learning difficulties and disabilities) is located next to Next Steps (the adult information, advice and guidance service). Staff work flexibly across the age boundary, with funding following the client. This means that if a Connexions worker has been helping a young person who turns 19, they can continue to work with them, providing continuity and support, and the help is counted as part of Next Steps figures, with funding allocated accordingly (Social Exclusion Unit, 2005b, p67)

6.67. Regarding transitions caused by leaving institutions or moving on from homelessness or being a refugee, once again this alerts us to the need for person centred support as well as co-ordinating and linking roles to facilitate positive resettlement and follow on support.

> **Positive support through transitions**
> Positive experiences of support in the context of transitions are evident where services have been targeted to respond to particular needs (e.g. age, gender or shared circumstances), and operate in a person-centred and holistic way. For services working with young people in transition, many may have multiple needs, including homelessness, substance misuse, offending, self-harm, prior physical, sexual or emotional abuse, mental health problems, being a victim of crime and young parenthood.
>
> Examples of well-received support services include Social Work Leaving Care Services (Rosengard and Jackson, 2005) and a specialist Social Work youth homelessness service that was the subject of user consultation in the course of a Best Value Review (Glasgow City Council 2003). Additionally, the literature review highlighted a wide range of voluntary sector services that are similarly valued by service users. In such services multiple and complex needs are addressed actively through networking and joint working. Moreover, it illustrates that services that are positively received services may be either statutory or voluntary.

6.68.   More generally the constraints on effective resettlement, and the potential for unsettled pathways at least for a period, have been found to include individual, situational and structural factors, including:

- A scarcity of housing or accommodation that matched need, including accessible and sustainable accommodation for people with physical health problems or disabilities
- Problems with practical issues such as paying bills, obtaining furniture, accessing information, or applying for a tenancy
- Lack of continuing support of the right kind, including low level housing support and support to address for example, mental health problems that may relate to prior abuse or trauma and be exacerbated by substance misuse; or people may be involved in continuing, increasing or relapsing substance misuse
- Negative social environments, where for example there is the fear of abuse or violence or pressured social networks
- Challenging or anti-social behaviour by the individual and associated reactions
- Lack of social networks and isolation and loneliness
- Lack of opportunities to move on through education, work or meaningful and structured activity (McNaughton, 2005; Rosengard et al, 2002; Petch et al, 2000)

6.69.   In turn, effective resettlement has been found to require a variety of approaches.

Promoting effective resettlement

-    Access to resources including: information and advice about housing and support services and options; decent quality, suitable accommodation in appropriate locations; required support and benefit maximisation, furnishings and community care grants.

-    A strategic, pro- active and persistent approach to support. If people are not there for pre-arranged visits, support workers 'stick with it' and keep trying to reach them.

- Needs led support that offers continuity and may involve partnerships or joint work – e.g. between generalist support services and a specialist mental health or alcohol service.

-    Options of access to mainstream or specialist services, recognising that some people may not want to use statutory or community-based services for privacy or other reasons.

-    Opportunity for some stabilisation for people who have chaotic life-styles or addictions – if for example a methadone script is needed, access to a GP may be critical.

- Opportunity to participate in community facilities and tenants/ residents groups where people can participate in decisions that affect them. However, not all those resettled want to participate, or are able to do so.

(Adapted from Rosengard et al, 2002)

SERVICE OUTCOMES

6.70.   In defining positive outcomes for people with multiple and complex needs from service provision, it is not possible to offer more than generalised statements, given the range of people the terms 'multiple' and 'complex' refers to. Additionally, given the significant shortfalls identified in current service provision (Chapters Three and Four) and identified good practice, quality of outcomes will be contingent on:

- The extent to which agencies have a strategic and holistic approach
- How well they listen to service users' views on their needs and preferences
- The extent to which they are pro-active and persistent in reaching and sustaining contact with service users
- How effectively they are linked with relevant service networks
- The effectiveness of joint working on the ground
- Their flexibility and capacity to acquire the best options for service users in the context of resource constraints.

6.71.   Rather than seeing quality of outcomes as being determined by the breadth and or intensity of people's needs, it should be seen as a routine challenge for services to work holistically to address the full range of service users' needs, and to assist people in moving on from the service provided.   It is however important to recognise that while service commissioners and many service users, including those with more intense needs, may only conceive of a good service outcome in terms of exiting from it once their needs have been met, this expectation may be inappropriate in the context of long-term, continuing needs. For a minority of service users with long-term continuing needs, who do not have families to care for them, and who require continuing accommodation and support, their current service, such as residential care, may be their 'home'. Providing that the existing service maximises their rights, meets good practice standards, enables people to develop and 'move on' within and through services and to maximise their quality of life, there may be no good reason for this not to be 'a home for life'.

6.72.   The 'maintenance' approach, as described by Keene (2001) accepts some people's preferences for not changing their status quo and proposes that ongoing support coupled with crisis-avoidance strategies should recognise such preferences. However, where the status quo involves significant risks it should not be accepted easily by professionals, without active exploration with service users of what is achievable.

6.73.   Notwithstanding those caveats, Hudson et al (2004) identified high level outcomes that will be outlined below (paras 6.89 and 6.90). Rather than being quantifiable, these outcomes relate to quality of life as perceived by the service user. This approach to outcomes is similar to that adopted in the DOH White Paper (DOH, 2005a) (see Appendix Three). Hudson et al state:

> *"It is important to be clear about the conceptual framework that comprises an outcomes - based approach. Outcomes refer to the effects or impacts on the welfare of service users and should be distinguished from outputs which are, strictly speaking, service product"* (Hudson et al, 2004, p4).

6.74.   It is important to recognise that outcomes measuring quality of life may be in tension with a target driven approach that characterises many services. For people with multiple and

complex needs a rigid adherence to outcomes of abstinence or length of time in accommodation, may lead to them being defined out of the service.

6.75. The importance of achieving softer outcomes as part of a process of moving towards achieving harder outcomes has been well recognised in Scotland. In the evaluation of the New Futures projects, additional assistance was offered to counteract the barriers people faced in accessing employment, such as addictions and homelessness, to enable people to enter or move nearer to the job market (McGregor et al, 2005). This is consistent with the approach of measuring distance travelled, as shown below.

Measuring distance travelled

Some homelessness organisations have developed 'distance travelled' measures. St Mungo's uses a tool called the 'Outcomes Star', while 'Off the Streets and Into Work' uses one called the 'Employment Map'. Both tools involve an initial assessment carried out jointly by a key worker and a homeless person who is using the service.

St Mungo's assessment maps the individual's situation in 8 areas: personal responsibility; living skills; social networks; substance use; physical health; mental health; meaningful use of time; and accommodation. Referring back to the initial assessment map later, enables the individual and the service provider jointly to clarify the individual's progress. Responses to trials of this tool have been very positive. One manager who has used the Outcomes Star said: "It's a useful tool for working with people with complex and challenging needs that enables us to track positive changes that could have been missed". A service user said: "It's a good way of understanding how I see myself. Each time I take the Star test, I can see a small step forward".

The National Institute of Adult Continuing Education has developed a similar tool for use by training providers in the statutory sector. The 'Catching Confidence' tool aims to record increases in confidence achieved through engagement with learning. Individuals discuss with their tutors situations that they find difficult to deal with.

These situations, and people's feelings about them, are then reassessed at a later date – usually at the end of a course. Progress is charted on a grid. The tool has been used by training providers, including further education colleges, probation services and voluntary groups (Social Exclusion Unit, 2005a).

6.76. Some of the literature stresses the needs for aftercare to be available if people are to sustain benefits of service engagements. This has been identified as particularly relevant to substance misuse services (Scottish Executive, 2002 b,c,d; SACDM & SACAM, 2003; Scottish Executive, 2006b), and to young people engaged with employability projects (McGregor et al, 2005).

JOINT WORKING

6.77.   Joint or partnership working is critical to addressing the problems of fragmented services resulting in poor service outcomes, and a number of initiatives described above have joint working at their core – for example, e-Care and the Argyll and Bute initiative, and in the case of *In Control,* a partnership between service users, carers and statutory services.

6.78.   Joint working is required at different levels – first, at the strategic service level, such as knowing the overall population with needs and what services are required, planning and commissioning services, and secondly, at operational level (see for example, Keene, 2001 and 2003; Rankin and Regan, 2004; DOH, 2006; Kennedy et al, 2001b).

6.79.   As so little is known about the overall population with multiple and complex needs, it is argued that relevant services across health and social care should collect and share information about populations or clients that they have in common (Keene 2001, Rankin and Regan 2004). Rankin and Regan further propose that "a statutory duty should be placed on the NHS and local authorities to collect data and monitor multiple service use" (p73).

6.80.   There are signs of movement in this direction in England, with the Department of Health stating that:

> *"The Director of Adult Social Services and the Director of Public Health will carry out regular needs assessments of their local population. This will require analysis and interpretation of data held by PCTs, local authorities, youth offending teams, the police, independent providers, voluntary and community organisations, Supporting People, the Department for Work and Pensions, census data and other data sources. This will enable the establishment of a baseline of current population needs in order to effectively plan for the future and provide the information needed to stimulate and develop the social care market"* (DOH, 2006, p166).

6.81.   An example of operational joint work that reflects the need for professionals' awareness of diverse community needs is shown below, and a further example is shown in Appendix 3.

Bromley-by-Bow healthy living centre – diverse services for a diverse community
The Bromley-by-Bow centre in Tower Hamlets provides a range of services, all co-located. People can see a GP, have a healthy meal, get information about other services and sign up for a course or exercise programme in one place. The centre is well-used and popular. One female service user who is 32 and has children has used the centre for almost 2 years. She commented, "Diabetes is a big problem in the Bengali community because our diet is richer. It used to be just fish and vegetables, but now it's more meat-oriented. Also, people stay at home more here than they would in Bangladesh, so they're not walking around a lot and don't exercise much." … "I really enjoy the exercise; I'd never be able to go to a gym because I don't drive and it's so expensive to join. The centre's a really happy place; there are always people laughing and it's a great place to socialise" (DOH, 2006a, p147).

6.82. Joint work requires appropriate resourcing and training for those involved in new ways of working. Commenting on care management in 2002, Stalker et al concluded that very little joint training had taken place, but that this was found beneficial where it had.

> *"Borders was one of the few authorities in Scotland to have organised joint training specific to care management, which had been independently evaluated. Staff reported that this had promoted a greater understanding of each others' roles". (*Stalker et al, 2002, p6).

6.83. Other recent studies in Scotland similarly indicate a high level of need for staff training to meet co-occurring and multiple needs better. (Scottish Executive 2006c). Additionally, guidance has increasingly emphasised the need for change in professional culture and values to promote the successful delivery of person-centred, creative and individualised approaches, as has recently informed guidance on mental health nursing (Scottish Executive, 2006g).

Angus Council – Training initiative to promote person centred planning (PCP)
Angus Council has developed its Skilling the Workforce initiative to train staff to work with service users in a person centred way. Its aim is for staff to allow service users to have as much control over their lives as they wish, to place them at the centre of decision-making, and to shift the locus of power and control from professionals to the individual. The user groups are Angus Council Social Work staff and the people who use the services. This extensive initiative covers up to 160 staff and 450 service users.

Initially 20 staff were trained to be PCP facilitators and 5 were trained as consultant facilitators by the National Development Team for PCP. To achieve PCP outcomes that involve more individualised and community-based support and life choices, staff must work differently. Elcap, a voluntary agency, was commissioned to train and equip staff with new skills, knowledge and approaches. The training covered: community building/ making connections; developing friendships/relationships; the role of local area co-ordinators and community mapping with people who have profound and multiple needs.

An Angus Social Work and Health service manager commented that "as the population of people with profound and complex needs is continually increasing, presenting ever more complex disabilities requiring complex and creative supports, we continue, in Angus, to place a priority on this area of our service delivery". By August 2006, all staff had been trained in using PCP and in a new tool Angus is piloting - 'Getting to Know'. This will replace the current review process to ensure ongoing planning and action towards what the person needs and wants. Other developments include:

- staff training in facilitating person centred reviews to find ways to involve people with high support needs and complex disabilities
- a mentor system for staff working with people who have multiple and complex needs. This involves support meetings, a mentor model, and a handbook and guidance.
- a service monitoring tool to assess the quality of service people with complex needs are receiving and to plan action to improve this.

- a partnership between Social Work and Health with PAMIS[13] to provide training for staff working with people who have complex needs. Allied Health professionals are also training staff in health care needs e.g. use of oral suction and gastrostomy feeding.
- A day centre manager is starting a post graduate level open learning module in Profound and Multiple disabilities (St Andrews University), to equip them with more enhanced skills and knowledge. Additionally, 3 day centre staff are enrolled on a certificated course in 'Approaches to People with Profound and Complex Disabilities'. (St Andrews University)

The effectiveness of all this training/ education will be evaluated. If successful the aim is for a rolling programme of this training for staff working with people who have profound and complex disabilities.

An individual with learning disabilities wrote of her experience: "I am taking more responsibility about choices in my life. I am doing this in a new way. This is called person centred planning." A staff member commented on working with a person with complex and profound learning disabilities:

> *"Although I have been working with S for 10 years, I felt overwhelmed at how little I knew and understood about her world. Using the PCP tools – particularly the essential lifestyle techniques – to gather information, I alongside her family and others closest to her, have learnt to step back and look at S's life from her point of view".*

(Community Care Works: Database of Good Practice in Community Care, University of Glasgow, updated through consultation with Angus Council)

6.84. This targeted training initiative illustrates the vision and the level of strategic and resource commitment that is required from policy makers, managers and staff to turn around professional values and approaches to promote new ways of working and to maximise rights, choice and control for service users.

Joint budgets

6.85. Rankin and Regan (2004) point out that positive and effective joint working will require procedures to rationalise funding streams and that the increasing popularity of pooled budgets indicates there is a will to act on this. The following example indicates the benefits of pooled budgets.

Pooling budgets in Redbridge
The London Borough of Redbridge operates a £40 million Section 31 Agreement (Health Act 1999) covering services such as social work, health visiting, school nursing, speech and language therapy, child and adolescent mental health services, educational psychology and educational welfare services.

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[13] Pamis refers to 'partnership with people with profound learning disabilities and their carers'.

> Pooling of budgets with the local PCT has smoothed the process of agreeing residential placements in particular, and has made supporting parent and children's visits less complicated. There is more clarity about the resources available to the partners and their priorities.
>
> Partnership working has become easier as the pooled fund is seen as being available to the population of children who receive a service from this part of the Children's Trust. Partners are more worried about whether the needs of the child concerned meet general criteria for a service and are less worried about whether their needs are primarily health, social care or education related (Department of Health, 2006, p164).

TARGETING SERVICES AND RESOURCE ISSUES

6.86.   Targeting and prioritising multiple needs and disadvantage is an intrinsic feature of social policy ranging from tackling areas of multiple disadvantage (areas for priority treatment) to the personal social services. Increasingly, various policy reports relating to people with complex/and or multiple needs specify a tiered approach to service provision. Although the number of tiers or levels deemed to be appropriate vary, all are based on the principal that people require different tiers or levels of service, depending on their needs (see for example SACDM and SACAM, 2003; Cox et al, 2004; Department of Health, 2005a).

6.87.   The level of service model is shown below in respect to the DOH model for people with long term conditions (DOH, 2005a.). Further information on key aspects of the NHS and Social Care long term conditions model is given in Appendix 3.

Level 3:
High complexity
Case management

Level 2:
High risk
Disease/Care management

Level 1:
70-80% of LTC population
Self care support/management

DOH, 2005a, p10

6.88.   The approach of targeting those in most need as a means of limiting eligibility for services in the context of budgetary constraints however is not without its critics. They alert us to the potential misguidance of a tiered approach that does not recognise that low level and early intervention can help to prevent crisis and worsening of people's situation (Hudson et al, 2004; DEMOS, 2005; Pratt et al, 2006).

SERVICE PRINCIPLES

6.89.   Having explored a range of good practice it is now relevant to focus on the principles that underpin good practice, and Hudson's recent work is useful here. Hudson et al (2004) have identified a series of principles that they relate to the preferred outcomes expressed in consultations with service users and other organisations. While these focused on older people their relevance to other needs has been examined and clarified. The principles stress that assistance and support should enable the following life opportunities and outcomes (Hudson et al, 2004):

- To access and sustain independence
- To be clean and comfortable
- To have a clean and predictable environment
- To be safe
- To access social contact and company
- To be active and alert
- To live healthier and longer lives
- To have an adequate income
- To contribute to the community
- To feel valued.

6.90.   Hudson et al identify 10 key principles (presented as models), that seem to be broadly consistent with the good practice identified from the literature covered in this review.

- *A whole person model* that tackles exclusion on a broad front – from low incomes and poor housing to promotion of good health and participation
- *A whole systems model* that maximises joint working in service access and delivery
- *A comprehensive model* that is preventative as well as responsive and covers a range of services
- *A user empowerment model* that is rights based, builds on the social model and maximises individual and collective participation – so tilting the balance of power to the service user
- *A reciprocal model* that stresses the contributions that people with multiple and complex needs can make, rather than focus on their problems or disabilities and dependence
- *A checks and balances model* – whereby central government sets and assesses the outcomes framework and its implementation, while localities determine how best to achieve these. Another check and balance is for service users to be involved at the start and throughout. Hudson et al note that guidance may be useful on participation.
- *A personalised service model* that is tailored to people's needs and views service users as the experts
- *A choice and diversity model* within which providers can be responsive to users' choices
- *A social capital model* which recognises the value of existing forms of informal support and community and user networks and cooperation
- *An implementation model* that stresses a coherent vision; building effective partnerships and develops realistic plans for delivery.
    (Hudson et al, 2004)

KEY POINTS – CHAPTER SIX

- Information on service availability must be readily available and in formats that are accessible to 'hard to reach' groups

- Services should seek to minimise waiting lists and make sure that they promote maximum opportunities for access in terms of factors such as physical location and accessibility, opening hours and appointment arrangements. IT can help promote accessibility for some

- Whole person needs must be addressed and met, rather than treating people's needs in isolation, if personalised services are to be provided. Single shared assessments and tools such as person centred planning can be useful for maximising service users' choice and control. Care or pathways plans are useful tools for setting out goals and service responses to achieve them

- Longer-range training and development programmes may be essential to generate cultures that support more personalised and creative approaches

- Single access points such as 'one stop shops' can improve various aspects of service users' pathways into and through services

- Outreach services that 'seek out service users' and 'stick with them' are valuable alternatives or can complement centre based services, not least for 'hard to reach' groups

- Professionals with a remit to link and co-ordinate support services, such as key workers, link workers or service navigators can help minimise the impacts of service fragmentation

- IT and information sharing can significantly reduce the need for service users to repeatedly give the same information to different services

- Service users (and where appropriate, carers) should be involved at all levels of service planning, development and delivery. Some will require advocacy to empower them to become involved

- Community development and peer education approaches are positive routes to empowerment and to enabling service users to contribute to influencing services

- Targets set for services should recognise that good outcomes from service provision for clients with multiple and complex needs are often not measurable in hard or quantifiable terms

- Joint work and partnership arrangements can make a big difference to service users experiences

- Meeting the needs of people with multiple and complex needs is resource intensive and is likely to involve for example, the pooling of information, the pooling of budgets and joint training

CHAPTER SEVEN: CONCLUSION AND IMPLICATIONS

INTRODUCTION

7.1.   This concluding chapter summarises the research, its key findings and its implications for policy and practice. The review's core aim was to explore what the literature tells us about the experience of people with multiple and complex needs in regard to their pathways through services. To this end the literature review drew on the fields of social policy, tackling social exclusion and disadvantage and meeting community care needs, as outlined in Chapter Two. Specifically the review focused on people's experiences of accessing services (Chapter Three), using services and moving within and through services (Chapter Four). The report then summarised the key gaps and deficits identified in service responses to people with multiple and/ or complex needs and considered what service users want (Chapter Five). Finally, Chapter Six explored evidence of good practice and related guidance to establish a framework for consolidating good practice and bringing about service improvements for people with multiple and complex needs.

7.2.   This final chapter will now summarise the key findings and lessons for policy and practice improvement, building on the key findings from the literature, outlined in the preceding chapters. To avoid repetition these will be presented in table format. First however, some general observations and points will be made in respect of the study and its findings overall.

COMMENT ON THE RESEARCH

7.3.   The core research focus was on people who have 'breadth and depth of need' (Rankin and Regan, 2004) and their experiences of obtaining and sustaining the assistance and support that they need to achieve positive outcomes.

7.4.   This study of the experiences of people with multiple and complex needs as service users has been challenging because of its interest in and coverage of a wide spectrum of needs and experiences at a time when new developments in policy and guidance proliferate.

7.5.   Implicit within the review of the literature were important differences in the depth or intensity of some people's needs, as reflected in the varying intensity of disability and illhealth. There were more obvious differences in the multiples of needs affecting people, with some having a duality of needs and others having a wide spectrum of needs. Additionally, the configuration of people's needs changed over time, reflecting aspects of motivation/ disposition and the interplay of service responses and structural influences.

7.6.   One notable gain from the wide scope of the study was that despite the wide variation in needs covered, common themes emerged strongly across the range of people's experience. Despite the range and diversity of the needs and experiences covered in the study, the literature review overall found some considerable consistency in the ways in which the key gaps and deficits, on one hand (Chapter Five), and what constitutes good practice on the other (Chapter Six), are perceived by policy makers and practitioners.

7.7.   Moreover consistent messages that emerged from the literature was that systemic and cultural aspects of service provision were key constraints on positive experiences and outcomes of services. The dimensions of restricted funding and bureaucratic commissioning, the fragmented structures and systems of service provision alongside professional divides, cultural and political (small 'p') influences on professional approaches (system rather than user-led), all interact to undermine the positive joint working required to achieve positive experiences and outcomes.

7.8.   Additionally, the literature indicates that the presence and consequences of multiple and complex needs, which in themselves magnify disadvantage, are further exacerbated by poverty and social and economic exclusion. In this light, some writers stress that improving opportunities for people with multiple and complex needs requires a social justice and equalities policy perspective (Rankin and Regan, 2004).

7.9.   The wide scope of the study however, means that the authors cannot make claim to full and comprehensive coverage of multiple and complex needs, their interconnections and their implications.

ADDRESSING THE GAPS AND DEFICITS

7.10.   While some of the service gaps and deficits identified were specific to responses to multiple and complex needs, others had wider relevance. Key points emerging from the literature were that:

- Overall there appeared to be a poor service response to multiple and complex needs which reflected the notion of the 'inverse care law' – those in greatest need often fare worst
- Poor co-ordination in planning and service delivery, together with a lack of networking and linking services that play a role in responding to multiple needs, created the context for people to fall between the service cracks or to experience a 'revolving door'
- The fragmentation of services, uni-dimensional or 'silo' vision and poor collaboration were 3 key institutional influences on poor outcomes
- Fragmentation is re-inforced by the structures and processes of commissioning and by fragmented and short-termism in funding regimes
- Deficits in the service response ranged across access to information and to services; communications; assessment; support and care planning and delivery
- Monitoring the use of services and of outcomes for people with multiple and complex needs and service use, itself tends to be fragmented and so does not provide a useful basis for planning
- The ethos and approach of individual agencies/ services and their systems, rules and criteria made a huge difference to the quality and outcomes of engagement
- Wider influences on poor services included evidence of resource constraints and inappropriate or unimaginative resources that inhibited creative solutions
- A lack of informed access to advocacy appeared to be a critical gap and could clearly make a difference to services received and outcomes.
- The extent to which services are networked with agencies working across the range of needs, and to which joint working is intrinsic to their service approach, made a positive difference.

7.11.   Despite these issues some service users felt very positively about some of the services they had received and had experienced positive outcomes. Moreover, many examples of good practice emerged from the literature.

7.12.   The following Table seeks to highlight good practice implications further by identifying the key factors that inhibit effective engagement with services, those that promote positive engagement and outcomes and service implications for improving the response to people with multiple and complex needs.

Table 7.1. Summary of good practice – Working with people with multiple and complex needs

Inhibitors of effective engagement	Factors promoting positive engagement and outcomes	Service implications
CORE THEMES		
Poorly targeted services Inappropriate resources	Personalised services, including methodology of person-centred planning with holistic approach	Personalisation Holistic 'whole person' approach Service user-led Consult carers Staff training needed Joint work Resource implications
Fragmented approaches Closed cultures/ inward-looking Partial responses	Joint work and effective partnerships and joint strategies/ action plans are required (e.g. Scottish Executive 2001c)	Agencies/ managers to promote and support networking, partnerships and positive joint work Promote through staff induction/ training Promote 'open' service culture
Centralised service models e.g. centre-based services Standardised approaches Narrow focus of needs assessment Lack of support or negative response at service reception	Link/ liaison and co-ordinating roles e.g. area co-ordinators Pro-active, responsive and flexible services that enable positive response to needs Positive reception/ referral	Consider need to promote access through linking and co-ordination mechanisms/ roles Develop new approaches and obtain resources in partnership Sustain positive, pro-active and collaborative service culture
Bureaucracy and fragmented services	Community development approaches Easy access points/ integrated front-line services for people with multiple/ complex needs in deprived areas particularly, but also more generally	Promote and sustain community involvement pro-actively Prevention orientation Resources
Standardised commissioning systems	Empowerment through enabling self-determination e.g. through direct payments (Department of Health 2005b)	Policy prioritisation Promote by maximising information and its take-up to a wider range of groups
Lack of access e.g. rural areas Also to accessible housing and services	Advocacy	Policy prioritisation Support to access advocacy Targeted investment e.g. housing and adaptations

Inhibitors of effective engagement	Factors that promote positive engagement and outcomes	Service implications
Lack of prioritisation and consistency of service user involvement and involvement of carers	Maximising service user involvement, as currently focuses at individual more than collective level	Promote consistent & sustained support for individual and collective involvement of service users and carers
Stigma and negative images, sometimes supported by policy messages e.g. refugees	Momentum to tackle stigma and promote positive images	Prioritisation, including at political level
SPECIFIC THEMES		
INFORMATION AND ACCESS		
Inability to get reliable, adequate information about services that may be available (Scottish Executive, 2006b)	Good information about service provision in local areas and about what services actually do	Review way information is made available, ensuring also that it is culturally and age- relevant and available in different languages and formats
Inappropriate referral systems, up to 28% of mental health referrals from primary care to specialist services are inappropriate (Social Exclusion Unit, 2004 b, p39) Failure to make appropriate referrals means that one problem often gets lost where people have complex or multiple needs (Humphreys, 2005; Scottish Executive, 1999)	Appropriate referrals including for those affected at times of service-related transitions e.g. from child to adult services and from generic adult to specialist older people's services; or from institutions to community services.	Professionals need knowledge of available services, their remits and protocols for referral. One stop approaches to service provision. Joint work at both planning and operational level.
People with mental health problems who are transferred from generic adult services to older people's services often face discontinuities of care just at the point at which their health needs are becoming more complex (Social Exclusion Unit, 2004b) The same problems apply with other service transitions	Holistic approaches	Seamless services Joint working Flexible application of service access criteria Flexible funding arrangements
Long waiting lists (SACDM & SACAM, 2003); Audit Commission, 2002b)	Timely access to services when the service user is ready to engage (Edwards, 2003; Homeless Link, 2002)	More efficient and effective referrals Increased resources to reduce waiting times
Inequities due to lack of access to translation and interpreting	Resourcing skills development to enable ease of access to translation and interpreting	Assess/ address deficits and gaps

Inhibitors of effective engagement	Factors that promote positive engagement and outcomes	Service implications
Appointments and opening times which do not suit people's lifestyles	Suitability of access times in relation to, for example, appointments and opening times (DOH, 2006) Ability to 'drop in' if problems arise and to re enter service if have failed to keep previous appointments (Rosengard et al, 2006)	More responsive services with flexible outreach and access to evening and week end services as required
PROMOTING POSITIVE ENGAGEMENT		
Fragmented delivery - 'pillar to post'	Integrated front-line 'one stop' services where people can receive all needed services (or information about them) within the one location e.g. Connected Care Centres (Rankin and Regan, 2004; Turning Point 2005)	Co-location of services. Turning Point suggest this is particularly necessary in areas of deprivation to address inequalities.
Services that are inaccessible to people without their own transport	Locally based services that are easily accessible (DOH, 2006)	Strategies to maximise locally based services including in areas of multiple deprivation
Multiple assessments and people "assessed to death" (Rosengard et al, 2002)	Single shared assessments that mean people's needs are only assessed once (Turning Point, 2005; Scottish Executive, 2004a; Scottish Executive, 2006d)	Introduction of Single Shared Assessments across services
Care plans imposed without adequate consultation and without taking account of a person's total needs including social, housing, educational and employment and leisure needs (Hudson, 2005)	Personalisation and service user participation in developing a care or support plan that takes a holistic view of people's needs (Demos, 2006; Scottish Executive, 2006b)	Holistic, 'whole person' approach needed that includes the service user and their carer in determining care plans Staff training needed
Failure to provide sufficient levels of, or appropriate support	Provision of more intensive and flexible support for people with multiple and complex needs (Scottish Executive, 2003 b,c; Department of Health, 2005 a,b; Scottish Executive, 2006e)	Increasing emphasis on prioritisation of needs according to levels or 'tiers'. People with multiple and complex needs placed in higher tiers and targeted to receive appropriate, flexible and comprehensive services

Inhibitors of effective engagement	Factors that promote positive engagement and outcomes	Service implications
Service users (whether geographically based or otherwise sharing common characteristics) are best placed to know the type of service they need (Turning Point, 2005; Scottish Executive, 2006b)	Service user involvement in shaping service delivery in addition to personalisation of care plans (Turning Point, 2005)	Increased use of needs audits.
Service users unable to access assistance to make their views known	Advocacy to clarify options & provide support (Scottish Executive, 2001a; Neale, 2004)	Increased commissioning of advocacy services
The various problems that people face in finding out what services are available to meet their needs. Also any constraints that prevent access to services, and the struggles, time and effort spent in doing so.	Link roles to enable people to find their way to and through different services. This role is described variably in the literature: e.g. *key workers* (SACDM & SACAM 2003, 2003, 2005c); *case managers* (DOH, 2006); *service navigators* (Rankin & Regan, 2004); *family support workers* (Gray, 2003)	New ways of working for many professionals and services.
Workers who do not understand the cultural and value base of service users and who have difficulty in communication where service users do not have English as a first language	Culturally, linguistically and gender appropriate services where the worker and service user share common understandings (Gray, 2003; Hodes, 2005)	Ethnically diverse workforce or access to interpreters Access to gender specific services
Passive response by services to service user inaction or "non-engagement" Poor follow up, e.g. where responses to dropping out from a service are limited to sending a reminder letter (Audit Commission, 2002b)	Active review and active outreach Active strategy and follow up where service user fails to attend appointments	Positive approaches to crisis prevention Assertive outreach and procedures in place to follow up clients who disengage/are in danger of doing so
Service users not feeling valued	Agencies and staff engage service users and carers and consult throughout Agency culture values participation and taking service users' and carers' views on board	Promote and sustain participative service culture

Inhibitors of effective engagement	Factors that promote positive engagement and outcomes	Service implications
MOVING FORWARD AND OUTWITH SERVICES		
Lack of systematic and joint planning for after-care and move on from services	Recognition of range of needs Joint planning for move on Resources targeted for follow on support	Aftercare to be planned as an integral part of service provision
Lack of recognition of range of needs and that some need follow on support for crisis prevention or response	Not all service users will exit services e.g. older people with long term chronic conditions are less likely to do so While some service users with multiple needs will exit services, many require aftercare, particularly to avoid lapses in e.g. substance misuse (SACDM & SACAM, 2003)	Aftercare to be planned as an integral part of service provision
Monitoring focuses on hard quantitative outputs (e.g. work done) and short-term outputs (i.e. numbers in tenancies)	Monitoring also focuses on 'soft' outcomes that identify what has improved or changed for service users as a result of agency interventions	Monitoring and evaluation to be prioritised within staff teams for reasons of accountability, best practice and positive outcomes Monitoring is built in to service review processes
Lack of monitoring and evaluation that incorporates service users views	The role of monitoring and the accountability of services to be explained to service users in service delivery process Service users feeling their views and experiences are valued and that they have a key role to play in influencing the development of services	Services develop strategies for involving service users in evaluation and monitoring, building on wider experience Range of methods can be employed e.g. service user consultative forum; service user representation in management Resource implications for developing and sustaining focus on monitoring/ evaluation and on involving service users will need assessed

IMPLICATIONS – IMPROVING THE RESPONSE

7.13.   Drawing on the experience of those with multiple and complex needs identified in this review, improving the response will require: information and advice about options by advisers who take a comprehensive approach and are sensitive to issues of multiple and complex needs; personalised, creative approaches; independent advocacy as a matter of right; assistance with navigating complex service systems; a focus on maximising individual and collective forms of participation and empowerment; responses that are sensitive to ethnicity and culture, and opportunities to try again.   More specifically, the literature suggests that service providers and policy makers need to address the following issues in addressing the needs of people with multiple and complex needs:

Strategic recognition in policy and practice

7.14.   Given that people with multiple and complex needs are some of the most vulnerable and excluded:

- Strategies to improve the response to people with multiple and complex needs should recognise that, while the problems faced by people with multiple and complex needs may reflect structural influences and wider needs in the community, these are likely to be magnified by additional difficulties
- Joint strategic planning should review how far commissioning and services on the ground promote social inclusion, an ordinary life and least restrictive options for people with multiple and complex needs.

Service planning and commissioning

Reviewing needs and services
- Blocks to accessing services must be addressed by all relevant providers. These include: poor built environments; low awareness of entitlements; long waiting lists and slow responses to requests for help; inadequate referral systems; stigma; lack of confidence to seek help, and limited service resources
- More knowledge is required about multiple and complex needs amongst some groups in particular in Scotland. There is a clear need to obtain a better picture of the needs of minority ethnic groups in Scotland given recent population movements, of groups such as gypsy travellers and of new minorities, such as immigrant workers.   Additionally, research could usefully focus on the perspectives of people with multiple and complex needs and on updating good practice in Scotland
- Rather than prioritise more research, there is a need for local joint assessment of gaps in services, followed by joint strategy development targeted to alleviate the blockages faced by people with multiple and complex needs. In the longer-term the evaluation of the Multiple and Complex Needs Initiative pilot projects may help to inform such planning
- Commissioners and providers should assess how best to engage services users in such joint assessments, building on statutory-voluntary partnerships
- Local joint planning should consider whether planning would be aided by an inter-service monitoring framework focused on outcomes for people with multiple and complex needs.

Commissioning
- Commissioners should ensure that appropriate services are in place to meet the needs of those with multiple and/ or complex needs
- They should further ensure that service targets do not mitigate against providing services for those with multiple and/ or complex needs who may need intensive support over lengthy periods of time
- In many instances, relevant targets for this client group may be soft targets that measure "distance travelled" rather than hard, quantifiable targets
- Options such as direct payments and other direct funding mechanisms that help to maximise user empowerment or 'self-determination' should be available to everyone, including those with multiple and complex needs.

Resources
- Meeting the needs of people with multiple and complex needs is resource intensive. Sufficient resources need to be available if people's needs are to be addressed holistically and if vulnerable peoples' revolving journey through various agencies, without resolution to their problems, is to be halted.

Access
- There need to be clear points of contact and easy access to user-friendly services
- As far as possible there should be open access criteria to services
- One stop, integrated and community based services should be considered.

The service response and communication
- This should be respectful, sensitive and pro-active
- Communication should be creative, skilled and be tailored to individuals.

Joint working and joint training
- Joint working needs to be prioritised at all levels, including in regard to strategic planning, service commissioning and at operational level
- Active and positive collaboration and partnerships are required to acknowledge the relatedness and interconnectedness of people's needs
- Joint training will be critical to awareness and understanding of different service roles, cultures and priorities
- Consideration should be given to the model of 'peer educators', as a route to empowering service users and towards 'educating' professionals
- Joint budgets and resource pooling will be necessary to overcome barriers of service protectionism and to ensure flexibility of response to identified needs.

Services and Models

Social model and meeting individuals' needs
- Services should promote opportunities for an ordinary life and social inclusion
- Services should develop an explicit strategy for counteracting the 'inverse care law' - ie service responsiveness to complex and multiple needs should be seen as a 'litmuss test' of general service performance
- Inclusion objectives are most likely to be achieved by services based on a 'social model', with a personalised and person-centred approach, rather than a

'medical'/diagnostic model, which is likely to re-inforce the fragmentation tendency and stigma

- Services and support should treat people with dignity and respect and strive to understand their individual (and multiple) needs.

Access to information and advice

- Services must ensure that clear, relevant information is available about what they provide and make sure that the information is in appropriate languages and formats to meet the needs of those people who have greatest difficulty in finding out about services/ and or benefit least from public services. These include people with low literacy levels, people from ethnic minorities, disabled people and people with long term health conditions, young adults with complex needs and excluded older people
- Information and advice should be accessible and all relevant information, advice and support should be accessible through single access points. This requires different services, such as health, social work, housing and benefits advice to collaborate. Locating such access points in areas of deprivation can promote inclusion in these areas and overcome, for example, transport difficulties
- People with multiple and complex needs need access to independent advocacy.

Assessment

- Services should assess the extent to which service users have multiple and/ or complex needs and are users of other services. Information should be shared between services on shared clients
- People's whole needs must be assessed and addressed holistically and in a person centred way. This should include social needs, such as the need for appropriate accommodation, meaningful activity and social networks. For community care groups (e.g. people with learning disabilities, people with mental health problems, older people) single shared assessments should be used and information shared between relevant services, whilst ensuring client confidentiality.

Support to address multiple and complex needs positively

- Services should adopt an ethos that views 'the problem' as caused by poor and inadequate service responses rather than by 'difficult clients'
- Support or care plans are needed that fully involve the service user (and where appropriate carers) in determining goals and priorities. These should be realistic and regularly reviewed in the light of changing circumstances. Such plans would form the basis of assessing service outcomes on an individual basis
- A named individual should be responsible for co-ordinating service users' support and ensuring that all the help they need, is accessed. Varied terminology is used in the literature for such a professional including: a care or case manager; a link worker; service navigator or in the case of NHS services, community matrons
- Given fragmentation, the role of some kind of 'link role', 'broker' or 'service navigator' may be essential. This will not lessen the need for independent advocacy and continuing support for people with multiple and/or complex needs to enable them to articulate their needs
- Active and intensive outreach models that seek people out, can make a difference

- Services should "stick with" people and recognise that some will miss appointments, relapse and/or at times may be reluctant to engage with services; continuity will be critical for some people
- Services should recognise that time limited interventions which seek to "cure" people of their problems are often ineffective if aftercare support is not available, and if other needs such as for decent accommodation and meaningful activity have not been addressed. This is particularly so where there are dangers that people might relapse as in cases of addiction and poor mental health
- Joint working is crucial as is co-ordination, collaboration and co-location to counteract 'silo' effect and stigma issues
- All the above have training implications and joint training can be a catalyst to good practice in pursuit of improving opportunities for people with multiple and complex needs.

CONCLUDING POINTS

7.15. This literature review is part of a continuing process and a first stage in a programme of work under the Scottish Executive's Multiple and Complex Need initiative that aims to identify lessons for improved service provision through a range of pilot projects. The evaluation of the initiative will build on and complement the learning from this review.

7.16. In terms of the range of themes covered in the literature that addresses multiple and complex needs, two apparent gaps emerged: firstly there was little specific focus on gendered experience, whether in relation to service users or carers, and secondly, the focus on the views of people with multiple and complex needs on their pathways in and through services appeared to be under-developed. The former would require gender awareness in research and monitoring, while the latter would require in-depth, user-focused and longitudinal research as well as user involvement in monitoring and evaluation.

7.17. The review has found that multiple and complex needs affect a wide range of people to varying degrees and with varying consequences. While the literature covered evidenced both excellent and improving practice, more generally it presented a bleak picture of the quality of responses obtained by people with multiple and complex needs, who continue to be significantly disadvantaged and excluded. It emphasised significant gaps in accommodation, advice, support, welfare benefits, monitoring and opportunities for inclusion. It stressed the need for more adventurous and creative joint strategies and partnerships that maximise the involvement of service users in increasing the effectiveness of the service response. It recognised that some people will not be ready to engage with what is on offer, but urged persistence. It also highlighted some significant shortfalls in funding of housing and support that must be addressed to meet needs, for those who require flexible outreach support of varying intensity and for those with profound needs who require higher levels of residential-based support.

7.18. Finally, there is a point about terminology to consider. While the research team have consistently applied the terminology of multiple and complex needs, it is worth commenting that there were some reservations in doing so because the terms are potentially stigmatising to service users. Most service users would not choose to go through a door labelled 'multiple needs' or 'complex needs'. Agencies should consider whether the term 'additional needs' is a better way of signifying the presence of breadth or depth of need.

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APPENDIX ONE - OTHER PERSPECTIVES ON 'MULTIPLE' AND/OR 'COMPLEX' NEEDS

1.   The Social Exclusion Unit (2005a)[14] focused on 4 groups of people considered to be particularly disadvantaged in using services, in their report on Improving Services, Improving Lives. These were: people with low levels of literacy; disabled people and people with long-term health conditions; people from certain ethnic minority groups and people who are multiply disadvantaged.   Until recently there has been no consistency of definition or usage of the term 'multiple needs' in the literature (Rioux and Bach 1994).   However by 2002, a consistent definition was increasingly being applied in the sphere of homelessness research.

2.   The ODPM (2002) refers to multiple needs in respect of homelessness, building on the definition developed and applied by Homeless Link in 1998, multiple needs relates to:

> *"A homeless or formerly homeless person who has 2 or more of the following problems and usually lacks effective contact with services: mental health; multiple substance misuse; personality disorders; offending behaviour; learning difficulties; physical health problems; challenging behaviour; vulnerability because of age". (Para 6.11.1) ... "If one of these needs were to be resolved, the others would still give cause for concern". ... "People with multiple needs may make frequent demands on many services, but not have their needs effectively by any". (Para 6.11.2).*

3.   In a similar vein, Clark in discussing new challenges in day services for a range of groups, uses the term 'multiple needs' to refer to people with disabilities 'whose behaviour is challenging to service providers' (Clark 2001), while other studies have stressed that a large proportion of disabled people have 'multiple disabilities' (Seed and Lloyd 1997).

4.   It should be noted that some of our key consultees stressed that multiple needs are prevalent in the mainstream population as well as among particular client groups. It was argued that rather than being a minority issue multiple needs are common to the life experience of most people at different stages or over time. The central problem to confront in relation to multiple needs in this context would be whether or not multiple needs are addressed or persist unmet.

'Dual diagnosis'

5.   From a health perspective and originating in the U.S., the term 'dual diagnosis' (or 'co-morbidity' has been commonly used to refer to the dual assessment of severe mental illhealth and substance misuse problems (NSF 2001). The Department of Health emphasises that the coexistence of substance misuse alongside mental health problems is common rather than exceptional (DOH 2002), while studies have identified that dual diagnosis is associated with poor prognosis, higher relapse and non-compliance with service regimes (Keene 2001).

6.   The term 'dual diagnosis' has been used, although less commonly so to refer to mental health and learning disability (Robbins 2000). The NSF recognises that there may be

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"many different definitions of the term 'dual diagnosis' " which may be used to describe "a number of complex or multiple needs".

> **In relation to 'dual diagnosis' or 'co-morbidity'**, the NSF identifies the relevance of Turning Points and other services. One particular service identified is the CASA Multiple Needs Service in London which was developed in 1995 to address gaps in service provision for people who experience mental health and substance misuse services in Islington and Camden. This service adopts a holistic approach "working with the whole person and their presenting difficulties. It also offers specialist training nationally" (NSF 2001).

'Complex needs'

7.   In *The same as you? Review* (Scottish Executive, 2000), 'complex needs' is defined as needs arising from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behavioural difficulties (Extract page 3). Further, the Glossary (page 128) states that 'complex needs' describes, "the needs a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour".

APPENDIX TWO - PREVALENCE RATES FOR PEOPLE WITH MORE THAN ONE SERVICE NEED

People with psychological and mental health problems

1.   Keene (2001) stresses the significance of psychological and mental health related complex needs, pointing to how these affect:

- around one fifth of the GP workload in the UK
- young adults and people with learning and development difficulties (Matson and Bamburg, 1998; Sturmey, 1998)
- men and women who make heavy use of health services
- 90% of those who attempt suicide (DoH, 1996)
- people affected by post traumatic stress disorder and substance misuse
- those with alcohol-related problems with multiple psychological, social and family consequences (MacRae and Cox, 2004 a, b)
- people diagnosed as having Attention Deficit Hyperactivity Disorder (ADHD) in later life, who have tendency to be involved in substance misuse (Tucker 1999).

People with co-occurring mental health problems and substance misuse

2.   The SACDM and SACAM report (2003) identifies that:

- Up to 3 in 4 drug using clients have been reported to have mental health problems
- Up to 1 in 2 clients with alcohol problems may also have a mental health problem
- Up to 2 in 5 people with mental health problems may have a drug/and or alcohol problems
- Co-morbidity in general practice in England has risen by 62% between 1993 and 1998.

(Source: SACDM/ SACAM (p.12), Scottish Executive 2003).

Women who have experienced domestic abuse

3.   Seventy percent of women psychiatric in-patients and 80% of those in secure settings have histories of physical or sexual abuse (DoH 2003, quoted in Baron, 2005).

4.   A study of 60 women using crack cocaine found that 40% reported being regularly physically assaulted by a current partner and 75% assaulted by a current or previous partner. Much of this was at the extreme end of the spectrum with approx 50% needing hospital treatment in the past year as a result of partner violence. (Bury et al, 1999, quoted in Humphreys, 2005).

Homeless people

5.   A Homeless Link survey of service providers to homeless people in 2002 found that:
- 88% of respondent agencies said they worked with clients with multiple needs
- 4458 service users were identified as having multiple needs, almost half (47.8%) of the total population receiving services
- multiple needs were most prevalent among rough sleepers.

(Source: Homeless Link, 2002)

People with learning disabilities

6.   A key Scottish Executive report commented that in Scotland:

"research suggests that 15-20,000 people need a lot of help to cope with daily living . Of these about 25% (4,000 to 5,000) are children and young people aged under 16. A further 25% (4,000 to 5,000) have complex needs which need a lot of support. People with learning disabilities are often not as healthy as the rest of the population. They may need more health support than primary care alone can provide. As people's learning disability becomes more severe, so does the likelihood of complex health needs such as epilepsy, mobility and sensory impairment. People with learning disabilities may need support and services because of mental health problems. Around 30% to 42% of children with learning disabilities may need help for emotional and behavioural problems. Older people with learning disabilities have more mental health problems. This is particularly so for people with Down's syndrome who may get early onset dementia"

(Source: Scottish Executive, 2000; see also Scottish Executive, 2006f).

7.   Learning disability is often associated with a variety of other disabilities and health problems, the most common of which include:

- Epilepsy (25% people with learning disability and 50% of those with severe learning disabilities)
- Hearing impairments (40%)
- Visual impairments (40%)
- Psychiatric and behavioural disorders (35%)
- Hypothyroidism in people with Down's Syndrome
- Dementia (especially people with Down's Syndrome and those over 50 years of age).

(Source: WHO quoted in Ridley, 2004.)

8.   McGrother et al (2001) using the Leicestershire register explored the extent of a range of problems. Overall, they found 43% of people with learning disabilities had a problem with one or more 'significant physical dependency', 42% had a 'significant behaviour problem' and 28% had one or more 'significant psychiatric symptom'. The overlap between problems was said to be "considerable". However they also found that mental illness such as depression in those with learning disabilities is often difficult to identify.

Older people with long term conditions

9.   A DOH Report (2006) identified that:

"An estimated 250,000 people with complex needs would benefit from case management, as required by the current Personal Service Agreements (PSA) target for long-term conditions.

(Source: DOE, 2006, p 116).

Young people with complex needs

10.   Ninety-eight per cent of respondents to a Social Exclusion Unit survey said that young people presented to a particular service with multiple problems.

(Source: Social Exclusion Unit, 2005b, p..27).

People with particular communication needs

11.   The Social Exclusion Unit identified that:

- one in 20 people have difficulties following straightforward texts accurately and independently
- one in 15 people have a sensory impairment who may require communication support
- around one in 7 people from ethnic minorities need information to be translated into another language (Social Exclusion Unit, 2005a, p.41).

People with challenging behaviour

12.   In terms of behaviour that is labelled as 'challenging', Hogg (2001) cited a recent study (Emerson et al, 2001), which found an overall percentage prevalence of 12.1% of the total population of children and adults as exhibiting 'challenging behaviour'. Variation across the age range was also found with the highest prevalence within the 10-19 year age group and those over 70+ years showing very little challenging behaviour. McGrother et al (2001) suggested a far higher estimate - 25% of the adult population with learning disability have a behaviour problem that poses a major challenge to the achievement of an ordinary life.

APPENDIX THREE - OTHER EXAMPLES OF GOOD PRACTICE

INFORMATION PROVISON

1.   The following example addresses the role of information provision in promoting awareness about health conditions for excluded groups.

> **Raising awareness of diabetes in hard to reach groups**
> Action Diabetes was launched in Slough in October 2004, to raise awareness of Type 2 diabetes in areas with populations most at risk. The project was designed and implemented by Dr Foster with the support of Slough PCT. Together they targeted hard to-reach groups using health needs mapping (HNM) analysis, in partnership with Experian.
>
> This targeted approach and the use of volunteers from the local community meant that people were advised on lifestyle changes before their condition worsened. Interim results showed that the 4-week campaign produced a 164 per cent increase in diabetes referrals among the most at-risk communities.
>
> "By using HNM we've been able to calculate where the highest concentration of undiagnosed sufferers are, and implement a local marketing campaign to target these groups. This campaign has finally given me the opportunity to engage with local communities on a larger and far more effective scale, mainly because of the local volunteers. Awareness levels seem to be greater than ever before."
>
> Source: DOH, 2006, p.167

IMPROVING ACCESS TO SERVICES

2.   The following five examples illustrate developments in one stop services and how technology can increase access to these.

> **Torry, Aberdeen**
>
> The aim of the project in the Torry area in Aberdeen was to provide a Community Neighbourhood Centre that local residents could use to get access to IT facilities and to provide a centre which brings services closer to the community. For the first time, through the Centre, all Torry residents should be able to access primary health care, community police services, social work, and housing functions within their own area.
>
> The Torry Neighbourhood Centre website provides information about the centre and services provided there and across Torry; with links to other local and relevant sites such as the new Community School, the Foyer Project and the Community Council website. All of this is available to the community via the Internet and touch screen databases.

The Torry community worked together to produce the information that is accessible on the touch screens and grouped into life events such as bereavement, education, health, information for children, parenting, etc. (Source: Scottish Executive 2003a, p.32)

The Sure Start programme

Established in 1999-2000, Sure Start aimed to provide one stop support services for families with children under 4 in deprived communities in England and Scotland, a number of which are in operation.

A recent Mapping Exercise of Sure Start services across Scotland identified, after a slow start, the increasing development and usage of Sure-Start services, with the majority being centre-based support services and 20% being outreach services. In the few local authorities where centre-based services were not developed at all this tended to be because this was not appropriate in rural areas.

(Source: Cunningham-Burley et al, 2005.)

Connected Care Centre Pilot, Hartlepool

Hartlepool PCT and Turning Point, together with local organizations, are currently piloting the Connected Care model. This model aims to provide managed transitions between services and be designed to fit the needs of the community.

One of the main features of a Connected Care Centre is a connected care audit undertaken by members of the community, together with professional researchers. This model builds capacity by enabling those within the community to gain experience of research and have the opportunity of working towards a qualification.

It is envisaged that each Connected Care Centre will have:

- a navigator for each client who will have an understanding of the local services, and be able to work with the services to provide a sustained and personalised pathway of care
- co-location of a variety of NHS, social care and voluntary professionals;
- common assessment procedure
- established procedures for sharing information
- shared training
- single point of entry
- round-the-clock support;
- managed transitions; and
- continuing support.

(Source: Social Exclusion Unit, 2005b, p.83)

Argyll & Bute Council – 3 Islands Partnership

It's 5.00am on a Tuesday in November. It's dark outside and the rain is lashing against the window. The start of a gale is brewing and you have to get up to make the first ferry off the island. Ahead of you lies a 3-day round trip to hospital in Glasgow to see your consultant for a ten-minute appointment. Your condition means when you return home on the last ferry on Friday night you will be exhausted.

Now, with the opening of the 3 Islands Partnership, public services have been brought together under one roof to provide a complete One-Stop shop service. These 'Servicepoints' are the first port of call for any queries from abattoirs to roads, and everything else in between. Each of the Servicepoints has videoconferencing equipment which any islander can use. In addition to this, computers have been installed so that islanders can access the Internet and, as the lead agency, Argyll and Bute Council has brought the 'information world' to the doorstep of some of its islands.

Each of the Servicepoints is managed by Council trained staff but regardless of how important the technology becomes in providing a link to services the Council also wants to ensure that facilities are maintained to provide the vital one-to-one contact that people need. To that end staff will always be available to Islanders in order that they can phone or drop into the Servicepoint and get advice about services (whether Council, business or health).

Partnership working is vital to Argyll and Bute Council because it offers opportunities not afforded to the Council working alone. The Three Islands Partnership means that the Council, Argyll & the Islands Enterprise Company, the NHS, the Scottish Executive and the local community companies are all working together to ensure that the residents of Islay, Jura and Colonsay are able to access services more easily with the use of technology. The 3 Islands Partnership is no longer a pilot project; it is rapidly becoming a way of life for many islanders.

(Scottish Executive, 2003a, pages 35&36).

E-Care and joint single shared assessments

3.   The benefits of e-care in conjunction with single shared assessments are highlighted below.

Emerging successes - E-Care and integrated assessments

The report on Evaluation of E-Care Projects in September 2005, highlighted a number of benefits, including:

- A reduction in duplication of information collected and held
- A reduction in repeat visits and repeat requests for information
- Cross-agency consent is consistently managed through an information sharing protocol

> - Information is readily and easily shared between the participating agencies
> - Cross-discipline and cross-agency working is fully supported
> - Local and national management information provision is made easier through the provision of granular information by the Single Shared Assessment (SSA) system.
> - A fully compliant electronic SSA system is in place (compliant with Assessment Review Co-ordinating Group National Minimum Information Standards for Single Shared Assessment for Older People). The SSA system records and supports the Indicator of Relative Need and Care Assessment Data Summary standards, allowing analysis and reporting consistent with national measures and data codification.
> - Approximately 700 staff have been trained to date and joint training has led to a greater understanding of other services' priorities and challenges.
> - Process mapping has provided huge benefits in confirming practices in each organisation, clarifying roles and responsibilities and clarifying terminology in use across organisations
> - Effort has been saved through use of the eCare organisational development toolkit, for business process mapping, risk assessment, communications and training plans.
>
> (Source; Scottish Executive, 2006a, p24; see also Audit Commission 2002a for a wider perspective on 'e-government')

IMPROVING SOCIAL AND HEALTH CARE THROUGH PLANNING, JOINT WORK AND PARTICIPATION

Setting clear outcomes

4.   The Department of Health emphasises the need for clear outcomes for social care and identifies these as:

- improved health
- improved quality of life
- making a positive contribution
- exercise of choice and control
- freedom from discrimination or harassment
- economic well-being and
- personal dignity.

(Source: Department of Health, 2005b)

Strategic planning and co-ordination

5.   The NHS and Social Care Long Term Conditions Model stresses the need for systematic planning, co-ordination and targeting services to meet needs. Two key stages are:

- to identify all long term condition patients in your health community
- to stratify the patients to match care to different needs of patients with reference to the following categories:

Level 3: Case management – Identify the most vulnerable people, those with highly complex multiple long term conditions, and use a case management approach, to anticipate, co-ordinate and join up health and social care.

Level 2: Disease-specific care management – This involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways, such as the National Service Frameworks and Quality and Outcomes Framework.

Level 1: Supported self care – collaboratively help individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively.

- focus initially on the very high intensive users of secondary care services through a case management approach
- appoint community matrons to spearhead the case management drive. In total, there will be 3000 community matrons in post by March 2007
- over time, develop a system of identifying prospective very high intensity users of services.
- establish multi-professional teams based in primary or community care with support of specialist advice to manage care across all settings.
- develop a local strategy to support comprehensive self care.
- implement the Expert Patient Programme and other self care programmes
- take a systematic approach that links health, social care, patients and carers.
- use the tools and techniques already available to start to make an impact

(Source: DOH, 2005a, p.6)

Participation

6.   In terms of process, the Expert Patient programme seeks to involve patients better in managing their own care.

Expert Patients Programme

The Expert Patients Programme (EPP) is a training programme run by the NHS for people who live with long-term health conditions such as arthritis, multiple sclerosis and asthma. It aims to develop new skills to enable people to manage their condition better on a daily basis and improve their self confidence. Piloted in 2002, it is now being rolled out nationally.

The programme is run over 6 weekly sessions of 2.5 hours each. Volunteer tutors, who themselves have long-term conditions, lead participants through structured course material covering topics such as relaxation and managing pain and medication. Each week attendees set action plans and also buddy up for support between sessions.

For those who do not feel comfortable engaging in a group situation, information and communication technology can provide a potential solution. During the EPP pilots, it was found that young men were reluctant to participate in the course. In response to this, a computer-based version of the course is now being piloted.

EPP Online provides a 6 week course for people with long-term health conditions. The course will be provided through a partnership with the Department of Health, the NHS and Stanford University. It will be available to 600 participants in England. People who have gained self-management skills through the programme can be expected to make around a 7 per cent reduction in GP consultations, a 10 per cent reduction in outpatient visits, a 16 per cent reduction in A & E attendances and a 9 per cent reduction in physiotherapy use.

The Programme is being adapted for non-English speakers and bilingual trainers have been recruited by working with local ethnic minority communities.

Source; Social Exclusion Unit, 2005a, p.87

Joint work

7.   Another key strand of the approach is that of joint work and integrated services, and one example is highlighted below.

Integrated care in West Sussex

People with complex needs require an integrated service, involving support from both health and social care professionals. Western Sussex PCT and West Sussex County Council (WSCC) are working in partnership with district councils and the voluntary and community sector to do just that through the Innovation Forum: Reducing Hospital Admissions project. Its main objective is to redesign care for older people with long-term chronic or complex health conditions around their needs and priorities, rather than around historic service models and professional roles.

The partners have established an intensive care at home service, which integrates intensive nursing, health therapies and hospital-at-home services with social and caring services home care service providing care for up to 6 weeks.

"This way is so much better. I'm getting more individual treatment, I'm eating better and I'm sleeping better than I was in hospital. In a hospital ward, you are just one name among many. At home you are getting personalised health care. The care staff who come here have more time for me than they would do in hospital." Hip replacement patient, home within 5 days of receiving treatment.

(Source: DOH, 2006, p.117)

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