



The Sainsbury Centre

for Mental Health

Choice Literature Review

**A Review of the Literature and Consultation on Choice and
Decision-making for Users and Carers of Mental Health
and Social Care Services**

by

Lesley Warner

Senior Researcher, Sainsbury Centre for Mental Health

Jeevi Mariathan

Senior Researcher, Sainsbury Centre for Mental Health

Simon Lawton-Smith

Senior Fellow in Policy, King's Fund

Chiara Samele

Head of Research, Sainsbury Centre for Mental Health

July 2006

Acknowledgements

The Sainsbury Centre for Mental Health and the Kings Fund would like to thank:

All the service users, carers and staff who took part in the focus groups and interviews, and made email contributions.

Everyone who took part in the expert panel meeting and commented on drafts of the report.

Those who contributed an international perspective on the choice agenda.

Alison Forbes for editing the report.

Contents

1	Foreword	1
2	Executive summary	3
2.1	Introduction	3
2.2	The Literature	3
	<i>Treatment choices</i>	3
	<i>Choice in care planning</i>	4
	<i>Service planning and delivery</i>	4
	<i>Advance directives and advance statements</i>	5
	<i>Direct payments</i>	5
2.3	The Consultation.....	6
2.4	An International Perspective	7
2.5	Conclusions	8
3	Introduction to the Choice Review	9
3.1	Background.....	9
3.2	Aims and Objectives	9
	<i>Aim:</i>	9
	<i>Objectives:</i>	9
3.3	Methods	10
	<i>Literature review</i>	10
	<i>Consultation with service users and staff</i>	10
	<i>Consultation with UK expert panel and international experts</i>	10
3.4	The Search for Literature	10
3.5	Structure of the Report.....	11
3.6	How to Read the Report	12
3.7	Exclusions and Omissions	12
3.8	Terminology	12
3.9	Examples of Good Practice	13
3.10	Methods, Tools and Media.....	13
	The Literature	
4	The Nature of Choice and Empowerment.....	14
4.1	Summary of Key Points	14
4.2	Introduction	14
4.3	The Policy Context.....	14
4.4	Key Publications	17
	<i>People with mental health problems</i>	17
	<i>People with learning difficulties</i>	18
	<i>People from Black and minority ethnic groups</i>	18
4.5	Information from the Literature.....	18
5	Treatment Choices.....	22
5.1	Summary of Key Points	22
5.2	Introduction.....	22
5.3	The Policy Context.....	23
5.4	Information from the Literature.....	24
	<i>Treatment choices</i>	24

	<i>Self-management programmes</i>	26
	<i>Children and young people with mental health problems</i>	28
	<i>Older people with mental health problems</i>	28
	<i>People with mental health problems, dual diagnosis, or substance misuse problems - life choices</i>	29
	<i>People with learning difficulties - treatment choices</i>	29
	<i>People with learning difficulties - life choices</i>	30
	<i>People from Black and minority ethnic groups - treatment choices</i>	30
	<i>Lesbian and gay people</i>	31
	<i>Service users subject to legal compulsion</i>	31
	<i>Assessing capacity for choice</i>	32
	<i>Medication choices</i>	32
5.5	<i>Examples of Good Practice</i>	34
	<i>People with mental health problems</i>	34
	<i>Children and young people with mental health problems</i>	35
	<i>People with dual diagnosis</i>	36
	<i>People with learning difficulties</i>	36
	<i>People from Black and minority ethnic groups</i>	37
5.6	<i>Methods, Media and Tools</i>	37
	<i>Key points on effective communication</i>	37
	<i>People with mental health problems</i>	38
	<i>Children and young people with mental health problems</i>	39
	<i>People with learning difficulties</i>	39
6	Choice in Care Planning	41
6.1	<i>Summary of Key Points</i>	41
6.2	<i>Introduction</i>	41
6.3	<i>The Policy Context</i>	41
6.4	<i>Information from the Literature</i>	42
	<i>The CPA for people with mental health problems</i>	42
	<i>Person-centred planning for people with learning difficulties</i>	43
6.5	<i>Examples of Good Practice</i>	44
	<i>People with mental health problems</i>	44
	<i>People with learning difficulties</i>	45
6.6	<i>Methods, Media and Tools</i>	45
	<i>People with mental health problems</i>	45
	<i>People with learning difficulties</i>	46
7	Choice in Service Planning and Delivery	47
7.1	<i>Summary of Key Points</i>	47
7.2	<i>Introduction</i>	47
7.3	<i>The Policy Context</i>	47
7.4	<i>Information from the Literature</i>	48
	<i>People with mental health problems</i>	48
	<i>Children and young people with mental health problems</i>	50
	<i>People with learning difficulties</i>	50
	<i>People from minority ethnic groups</i>	50
	<i>Older people with dementia</i>	51
	<i>Examples from general health care</i>	51
7.5	<i>Examples of Good Practice</i>	51

	<i>People with mental health problems</i>	51
	<i>Children and young people with mental health problems</i>	52
	<i>People with learning difficulties</i>	52
	<i>People with dementia</i>	53
	<i>Good practice example from general health care</i>	53
7.6	Methods, Media and Tools.....	53
	<i>Children and young people with mental health problems</i>	53
8	Advance Directives and Advance Statements	54
8.1	Summary of Key Points	54
8.2	Introduction	54
8.3	The Policy Context.....	55
8.4	Information from the Literature.....	55
	<i>Models of advance directives</i>	55
	<i>Evaluations of the use of advance directives</i>	56
	<i>Advance directives for people with dementia</i>	58
8.5	Examples of Good Practice	59
	<i>People with mental health problems</i>	59
	<i>Older people with dementia</i>	59
8.6	Methods, Media and Tools.....	60
	<i>People with mental health problems</i>	60
9	Direct Payments	61
9.1	Summary of Key Points	61
9.2	Introduction	61
9.3	The Policy Context.....	61
9.4	Information from the Literature.....	63
	<i>Projects to encourage uptake of direct payments</i>	63
	<i>Barriers to uptake of direct payments</i>	65
	<i>Evaluation of direct payment schemes</i>	66
	<i>Limitations of direct payment schemes</i>	67
	<i>Direct payments for people with learning difficulties</i>	68
	<i>Direct payments for people from Black and minority ethnic groups</i>	69
	<i>Future developments</i>	69
9.5	Examples of Good Practice	70
	<i>People with mental health problems</i>	70
	<i>People with learning difficulties</i>	71
	<i>Older people, and people from Black and minority ethnic groups</i>	71
9.6	Methods, Media and Tools.....	71
	<i>People with mental health problems</i>	71
	<i>People with learning difficulties</i>	71
	The Consultation	
10	Focus Groups, Interviews and Email Contacts	73
10.1	Summary of Key Points	73
10.2	Introduction	74
10.3	Method.....	74
10.4	Findings	74
10.5	The Nature of Choice and Empowerment.....	76
10.6	Treatment Choices	77

10.7	Medication Choices	77
10.8	Self-Management Programmes	78
10.9	Choice in Care Planning	78
10.10	Choice in Service Planning and Delivery	79
10.11	Primary Care.....	79
10.12	Choice of Professionals, and Professionals' Attitudes	80
10.13	Carers	80
10.14	Time Spent with Professionals.....	80
10.15	Advance Statements and Advance Directives	81
10.16	Direct Payments	81
10.17	People from Black and Minority Ethnic (BME) Groups.....	82
10.18	People in Forensic Settings	82
10.19	Young Service Users	83
10.20	Contributions via Email	85
	<i>In Control - services for people with learning difficulties</i>	85
	<i>People from Black and minority ethnic groups</i>	86
10.21	Examples of Good Practice	86
10.22	Methods, Media and Tools.....	86
	The International Consultation	
11	An International Perspective on Choice in Mental Health.....	87
11.1	Summary of Key Points	87
11.2	Introduction	87
11.3	Australia.....	88
	<i>A perspective from Australia - Steve Morris</i>	89
11.4	New Zealand.....	91
	<i>A perspective from New Zealand - Judi Clements</i>	93
11.5	United States of America	94
	<i>New York</i>	96
	<i>A perspective from New York - John Allen</i>	97
11.6	Canada	98
	<i>A perspective from Canada - Penny Marrett</i>	99
12	Conclusions	100
13	References	102
14	Appendix	130
14.1	Members of the Project Team.....	130
14.2	International Experts	130
14.3	UK Experts.....	130
	<i>Members of the expert panel</i>	130
	<i>Other contributors</i>	130
	Tables	
Table 1.	Participants in focus groups and interviews	75
Table 2.	Email participants	75

1 Foreword

Choice is generally considered to be a 'Good Thing'. As a concept, it underpins much of the reform of the NHS that is taking place at the moment under the banner of 'Creating a Patient-Led NHS'. The expectation is that giving patients increased choice over the care they receive will empower them, diversify the range of available services and providers of services, and drive up standards and quality through competition. It is also intended to reduce inequalities by providing equitable choice to all health service users.

In the words of Health Minister Rosie Winterton [1] *'Better health care outcomes are achieved when.... both patient and health professional share in making decisions about treatment and care. The quality of consent for treatment is improved, people take a more active role in managing their health and health professionals are better supported to provide a level of healthcare and choice that they can take great pride in and that people increasingly expect.'*

The government's vision for choice in mental health is set out in *Our Choices in Mental Health: A framework for improving choice for people who use mental health services and their carers*. Their vision for people with learning difficulties, *Valuing People; a new strategy for learning disability for the 21st century*, similarly outlines the issue of choice for this group of service users.

Both documents cite examples of good practice alongside a broadly aspirational approach. The reality for many people who use mental health services is, as this literature review demonstrates, mixed. This is perhaps not surprising. At an organisational level, commissioners of services will have different ideas about what range and level of services are required to meet their population's mental health needs from within limited resources. At an individual level, mental health practitioners will have their own professional view about the care and treatment they offer. Service users' experiences will vary - some will praise their psychiatrists' willingness to allow them to discuss and choose between various treatment options; others will say they were just told to take the pills.

We have found in this review that, despite examples of good practice, the government's vision is still a long way from becoming a reality for many people who use mental health services. Introducing choice in mental health and learning difficulty services raises many difficult questions. Does choice lead to confusion rather than clarity? What information and support enables people to make an informed choice? How do you commission a range of services to ensure that choice is meaningful? How do health professionals feel about taking on board patients' preferences, which may not be their own? Are carers listened to? What happens if people choose badly? Who should make decisions when a person lacks the capacity to make them for themselves?

We hope this review will help answer those questions, by focusing on the literature from the past 5 years, which discusses choice in mental health, especially good practice. This review demonstrates that while some issues have been discussed at length, others are noticeable by their absence. For example, we found a

considerable amount of work around advance directives and direct payments, but scant literature on choice for people in the criminal justice system, including prisoners, who we know experience very high levels of mental health problems.

This review approaches the literature thematically. There are separate sections on the nature of choice and empowerment; treatment choices; choice in care planning; choice in service planning and delivery; advance statements and directives; and direct payments. In each section we have summarised the evidence from the literature and highlighted good practice and the methods, media and tools which may be used to implement it.

The review also reports the findings from a number of focus groups that were asked to consider choice in mental health, and looks at how choice is reflected in national mental health policy and guidance in four other English-speaking countries.

Patient choice, across all health and social care provision, is likely to maintain its high profile over the next few years. We hope this review will help to clarify the current position for people who have a mental health problem or learning difficulty and their carers, as well as those who provide them with treatment, care and support and service planners and commissioners.

[1] Better Information, Better Choices, Better Health, DH, December 2004.

2 Executive summary

2.1 Introduction

This literature review on choice in mental health was commissioned by the Department of Health in July 2005 and submitted to the Department in January 2006. The main part of the review looked at the English language literature on choice in mental health over the past five years. It aimed to identify in particular what tools there are to help people make meaningful choices; what media are effective in facilitating decision-making; and to what extent methods such as advance directives might be used. The review also included a consultation exercise and an overview of how choice is reflected in national policy and guidance in four other countries.

2.2 The Literature

An electronic literature search was undertaken by librarians at the King's Fund and Institute of Psychiatry, accessing a wide range of databases and publications. This was complemented by hand searches of journals and web sites. Altogether 392 publications were included in the review. The results are presented under six themed headings, as below.

The nature of choice and empowerment

Core principles for promoting choice for people in all client groups include acknowledging that people have the right to choose their treatment, and that choice applies across the spectrum of care. Service user empowerment is a crucial first step towards enabling people to make choices about their health and other aspects of their lives.

Advocacy and support services can help service users exercise choice, but this is only practical if adequate resources are provided to ensure options are available to support individuals' choices. As a step to achieving this, new access points into mental health care should be developed, for example in libraries and walk-in centres. It is also clear that service users want better information on their options, using a variety of media, and access to self-management programmes, advance directives, direct payments and individual budgets.

To ensure choice becomes a reality for all client groups, issues of inequality, which affect some groups such as people from minority ethnic groups and those with learning and communication difficulties, must be addressed.

The bottom line is that achieving service user empowerment and involvement requires adequate financial resources along with a positive commitment from professional groups, who must be prepared to give up some of their power.

Treatment choices

The literature makes it abundantly clear that service users want to be offered more than just medication: they want access to talking therapies, services which take account of their gender, culture and ethnicity, and self-management programmes

which are orientated towards recovery. When medication is the preferred option, service users want full information on its effects and side effects. They also want to be able to choose traditional medication in preference to atypicals, and to be given support when they choose to stop taking medication.

Unsurprisingly, service users in all client groups need information and support to help them make informed choices. It is also important not to forget that carers for children and young people, people with learning difficulties, and older people with dementia need information and support to make decisions on the service user's behalf.

There are some key points about good practice in communication in a variety of written and other media which apply generally to all service users groups, and particularly to those for whom communication is difficult. In particular, the Mental Health Foundation and Values into Action are two of the organisations which have published information on how to help people with learning difficulties exercise choice. Alongside this, self-management programmes devised by the Mental Health Foundation, Rethink, and the Expert Patient Programme all provide valuable information on how mental health service users can take an active part in working towards recovery.

Under the Department of Health's *Access, Booking and Choice* initiative, many mental health services have improved access and facilitated service user choice in areas such as outpatient appointments and referral processes between primary and secondary care services.

Choice in care planning

The Care Programme Approach (CPA) and Person Centred Planning (PCP) provide the frameworks for planning, delivering, monitoring and reviewing the care of people with mental health problems and learning difficulties. There is widespread agreement in the literature that mental health service users and their carers should be fully involved in CPA care planning, including in the assessment of risk. People with learning difficulties and their carers should be fully involved in PCP as a way of supporting personal choice.

The evidence demonstrates that mental health service users who are involved in their own care planning are more satisfied with the services they receive than those who are not involved. However it is also very clear that currently many service users and carers are not meaningfully involved.

The Royal College of Psychiatrists has published leaflets and checklists to help service users, psychiatrists and carers with the care planning process, and Valuing People has produced easily accessible information on PCP. As with other aspects of exercising choice, service users may need help with care planning from advocates or support workers.

Service planning and delivery

Involving service users in the process of service planning and delivery is not the same as enabling them to make choices about the services they would like to

receive, but without involvement they can have no impact on the future direction of care provision.

The literature suggests that organisational culture and professional opposition often prevent service users from becoming fully involved in the planning, delivering and monitoring of mental health services, although there are some examples of where this is working well, and a range of materials designed to support service user involvement. Certain groups of service users are particularly poorly involved in the service planning process, such as people from Black and minority ethnic groups, older and younger people and people with a diagnosis of personality disorder.

In terms of facilitating and encouraging involvement, having mental health service users as members of NHS Trust Boards, and involving them in staff selection, enables them to help shape the organisations which provide services. Ways have been found to involve people with dementia in staff selection and service commissioning. People with learning difficulties have been appointed as joint chairs to some of the local Partnership Boards, and ways have been found to enable service users to contribute to strategic planning. Young Minds has produced a guide to good practice in involving young people with mental health problems in planning the sort of services they would prefer to use. Service user organisations can also, independently, have an impact on service development through influencing commissioning decisions.

The impact of service user involvement in care planning and delivery is under-researched and under-evaluated. It is difficult to be sure to what extent service users' expressed choices actually lead to changes in services, although some examples of this can be found in the literature. This is an area where more work could be useful.

Advance directives and advance statements

Advance directives and advance statements allow individuals to express their views about future treatment preferences and refusals should they become incapable of expressing those views at the time. The literature reflects that mental health service users are keen to use advance directives and advance statements to make their wishes known, and they can also be used by people with dementia. However they are only slowly being adopted in the UK. Some psychiatrists are unconvinced about their value, and some are reluctant to respect their validity.

To be effective, it is important that support is available to help service users draw up advance directives and advance statements. Happily, information and guidance on them is widely available.

On the particular question about whether advance directives and advance statements contribute to helping prevent emergency and compulsory admissions to hospital, the findings are so far inconclusive.

Direct payments

Direct payments are paid to an individual by local authority social services departments as an alternative, or in addition to, direct service provision, with the aim

of improving recipients' quality of life. Recipients can use the payments for a wide range of services, and can choose to buy personal support and respite care or to access leisure, education and social opportunities.

Direct payments are potentially available to people with mental health problems, and those with learning difficulties, in all age groups. However the uptake of direct payments nationally for people with mental health problems or learning difficulties has been slow, despite local authorities having a duty to offer them to service users, and a number of initiatives to promote their use. It is clear that staff in some services are not yet committed to supporting service users in using direct payments.

As in many areas involving choice, support in arranging and managing direct payments is crucial for service users. Service users who have been supported to make use of direct payments have been very satisfied with this tool to increase their choice of care provider.

Reservations have been expressed about the potential risk for service users employing untrained or unsupervised staff, and the problems service users may have in managing budgets, though this could be overcome by providing formal support, or managing agents or brokers. In addition, direct payments are of limited use if there is not a local choice of service providers. However where they have been implemented the experience of service users receiving direct payments appears to be positive, with an increase in independence and choice cited.

2.3 The Consultation

Focus groups and interviews were conducted to gauge the views of service users, carers, and practitioners on how choice and decisions are made about care, and the tools that help service users and carers make meaningful choices. In addition, some people took part in the consultation via email. Altogether 38 service users, six carers (one of whom was also a GP), and five staff members made a contribution, along with the director of a national voluntary organisation and three members of a PCT forum for people from Black and minority ethnic groups.

It was generally agreed that service users have limited choices at present about their mental health care and lifestyle. This raised questions around empowerment. It was felt that attitudes of professionals need to change so they no longer marginalise and disempower service users, and service users would like to choose who they see. Appointment times with GPs and psychiatrists need to be long enough to enable an adequate discussion of the options to take place. There should be to be wider treatment and medication choices, with more opportunity to discuss options with professionals. In addition, carers feel their views and preferences are not adequately considered.

There is a need for meaningful involvement between service providers and service users. Interestingly, participants were significantly happier with voluntary sector providers than with the statutory sector, which they felt did not encourage service user choice or promote an adequate range of service options.

As uncovered in the literature review, the question of support and information for people in making choices was highlighted. Choice can be complex. Advocacy and support workers are needed to support service users in making informed choices and people need appropriate and sufficient information to enable them to make informed choices. In particular, there needs to be more information on, and availability of, alternative therapies, from both statutory and voluntary sector providers, and self-management programmes should be more widely available.

The consultation confirmed that service users want to be involved in planning their own care and to have a genuine partnership between them and service providers. To help service users make informed choices at an early stage, better information on mental health services and treatment options should be available from GPs and primary care services. Reflecting the literature, service users want more information on advance statements and direct payments in order to decide whether these would be useful for them, and were concerned that they would have adequate help and support if they were to opt for them.

Some particular groups had specific concerns. People from BME groups want to be able to choose culturally appropriate services; people in forensic mental health settings feel their ability to make choices is especially limited; and young service users also feel unable to exercise choice due to a lack of information on the options, and to services' focus on the needs of adult service users.

2.4 An International Perspective

In a selective overview of where choice issues sat within national strategies and policies on mental health in Australia, New Zealand, the United States of America and Canada a number of common themes came to the fore.

First, the language of choice is not universally used, and it is hard to locate any free-standing documents looking specifically at patient choice in mental health. However often choice issues are implicit in publications that refer to patient empowerment, involvement and participation. More recent documentation uses the language of choice more frequently, as it gains hold as a central principle for developing services.

Choice is seen as a vital ingredient in the recovery model of mental health care, without which people's recovery and integration in society is significantly hindered, and people cannot regain control of their lives.

As found elsewhere in the Review, good information is crucial if choices are to be meaningful, along with support for people to help them make often complex choices. With the help of professionals and advocates, people with mental health needs should be able to access good quality information not only about their health care but about all aspects of their lives, such as housing and employment.

In the countries studied, there is broad agreement from governments, service providers, service users (generally referred to as consumers) and carers that service users should have more, and better informed, choice. However in practice choice is not commonly available. This may arise from health professionals' reluctance to

offer choices, or though limitations on available services, primarily as a result of financial constraints. Having a choice is meaningless if there is not a range of affordable, culturally sensitive and appropriate services from which people can choose. There are clearly lessons here for the implementation of choice for mental health service users and carers in the UK.

2.5 Conclusions

A review of all the findings from the literature, consultation and international perspectives brought us to the following overall conclusions.

Making choice a reality is no easy task, but it is essential if mental health service users are genuinely to be placed at the centre of a Patient-led NHS, as the government intends. Although choice is by no means a reality for many who use mental health services (and the UK is not alone in this), there are clear benefits for service users in pushing forward efforts to increase the choices they have.

The opportunity exists to study the examples of good practice we have identified, and understand better how mental health service users are benefiting from being empowered to make decisions about both their health care and life choices.

The challenge for everyone involved in mental health is to ensure that there is both the will and the resources made available to replicate this good practice more widely. Choice clearly has a central role to play if we are to improve the daily experience of people with mental health problems and support them on the road to recovery.

Mental health has often been referred to as the 'Cinderella service' within the NHS. Equality will only come if mental health service users are offered the same choices about their care as people with physical health needs. We hope this review will help turn that aspiration into a reality by applying many of the key findings and issues from the research and other literature into service development and practice.

3 Introduction to the Choice Review

3.1 Background

Choice can be defined as the power, right, or liberty to choose. Choice also implies having the freedom to choose from a number of options. For people with mental health needs, choice can be about selecting a particular service, treatment or care option from a range of possibilities. It can also be about deciding *not* to use a particular service, treatment or care option. It can include making known a choice of treatment or care option to be put in place at some future point.

Mental health service users' ability to make choices may be constrained by their own limitations (lack of knowledge, information, capacity), others' shortcomings (lack of appropriate and available services, staff unreceptive to the principle of user choice, restrictive referral processes), and by legal constraints imposed on those who are subject to compulsion under the Mental Health Act 1983. How service users make and communicate their choices also needs to be considered; there may be particular problems for people with learning difficulties, those with some form of mental impairment, those with communication difficulties due to auditory or visual impairment, people who communicate non-verbally, and those for whom English is not their first language. In addition, the choices of carers may be at odds with what service users would choose for themselves.

There has been no shortage of government policies and guidance on choice relating to health in the past few years, some of which directly or indirectly concerns health and social care for people with mental health problems and those with learning difficulties. These policies and guidance are described in this review.

3.2 Aims and Objectives

The aim and objectives of the review were set in the NIMHE tender document of July 2005. These were:

Aim:

To provide a review of the literature on choice and decision-making in mental health and social care for people with mental health problems and carers, and identify in particular:

- what tools there are to aid those with mental health problems and their carers in making meaningful choices about their care;
- what media are effective in facilitating decision-making for people with mental health problems;
- to what extent methods such as advance directives might be used.

Objectives:

- to review the choice literature on issues concerning: a) promoting and supporting life choices, b) access and engagement, c) assessment, and d) care pathways;
- to judge the quality of the available literature using a critical appraisal framework;
- to identify and report on examples of good practice

3.3 Methods

Literature review

English language literature was examined to provide a comprehensive information set relating to the available tools by which users and carers can make meaningful choices, to identify the type of information and communication systems necessary to enable user and carer choice, the range of currently used methods, such as advance directives and direct payments, and other potential methods, and to examine the extent to which they can be used to enhance service users' choice and the responsiveness of services. A critical appraisal framework was devised and used to select for inclusion only literature which was relevant and of high quality.

Consultation with service users and staff

Focus groups and interviews were conducted across the NIMHE regions to gauge the views of service users from the various client groups, carers, and practitioners on how choice and decisions are made about care, the tools that assist users and carers make meaningful choices, the media that are effective in helping users and carers make informed decisions about their care, and what methods are available to them such as advance directives. Issues around access and engagement, assessment and care pathways were also explored.

Focus groups and interviews took place in services we had identified as examples of good practice generally, not just in relation to the choice agenda. In addition, some people took part in the consultation via email. Altogether 38 service users, six carers (one of whom was also a GP), and five staff members made a contribution, along with the director of a national voluntary organisation and three members of a PCT forum for people from Black and minority ethnic groups.

Consultation with UK expert panel and international experts

An expert seminar was held to discuss the preliminary findings from the literature search and the consultation. Delegates included service user and carer representatives, practitioners and other key experts (see Appendix). Members of this panel and other experts were also asked to comment on the draft report.

International experts (see Appendix) were also asked to contribute to the review by providing information on the choice agenda in the USA, Canada, Australia and New Zealand, and by commenting on the draft report.

3.4 The Search for Literature

Searches were made by librarians at The King's Fund and the Institute of Psychiatry of the following electronic databases: AGEINFO, ASSIA, British Library Integrated Catalogue, British Nursing Index, CINAHL, DH Data, Embase, King's Fund, Medline, PsychINFO, National Research Register, PubMed, ReFeR and Social Care Online.

Keywords used to search included: Mental health problem(s), mental health disorder(s), learning disabilities, learning difficulties, older people, choice(s), empowerment, participation, decision making, options, advance directives, and direct payments. Only literature in English, published since 2000 in the UK, USA, Canada, Australia and New Zealand, was searched, although some articles meeting these

criteria referred to mental health policy and practice in Europe, Hong Kong and Japan. A small number of key documents published before 2000 were included.

The criteria for inclusion of citations was kept deliberately broad, to reflect the wide range of services and people with mental health problems, including children, older people, adults of working age, people with learning difficulties, people from Black and ethnic minority groups, hard to reach populations (e.g. substance misusers, homeless people, refugees) and other traditionally excluded groups, such as people with personality disorders and those with profound and severe learning difficulties.

We identified many references which included as key words 'consultation', 'involvement', 'participation', 'engagement' and 'preference', rather than 'choice'. We recognised that initiatives to help service users have a voice is not the same thing as giving them a choice. Therefore, we only included such references when the issue of choice seemed to be implicitly addressed in the publication.

Some examples of good practice, along with information on various methods, media and tools to facilitate choice, were found on a number of organisations' web sites, as well as through other types of publication. Web site addresses were found through published articles, using Internet search engines, and via links from other web sites. Inevitably, those listed represent only some of the available sources of information.

A total of 1,708 references was identified by means of the electronic searches, from which 263 were selected for examination on the basis of their abstracts. Approximately 192 additional references were identified through searching the web sites of statutory (e.g. Department of Health, NIMHE) and voluntary organisations (e.g. Mental Health Foundation, Rethink, Joseph Rowntree Foundation, Values into Action), and through personal resources. Altogether 475 publications were initially judged to be relevant and examined in detail, of which 392 were subsequently used in this review. The literature included research papers, policy documents, reports, leaflets, and information published on web sites.

3.5 Structure of the Report

This report examines several aspects of choice in relation to mental health and social care for people of all ages with mental health problems or with learning difficulties. Separate chapters deal with topics which emerged from the literature: the nature of choice and empowerment; treatment choices, including choices in medication, talking therapies, and access to alternative self-management programmes; choices in care planning; choices in service planning and delivery; the use of advance statements and advance directives; and the use of direct payments. In each chapter we include an overview of the policy context, the emerging themes, examples of good practice, and the methods, media and tools that are being used. Key points are summarised at the start of each chapter.

Where there is specific material relating to people in particular service user groups (people with mental health problems; people with a dual diagnosis; children and young people with mental health problems; older people with dementia; people with

learning difficulties) or to those from marginalised groups (people from Black and minority ethnic communities; gay, lesbian and bisexual people) we make this clear.

Evidence from our consultation with service users and staff is presented using a similar framework to that of the literature review.

The views of the UK expert panel, some of whom were able to attend a half-day discussion on the emerging findings from the literature review and focus groups, and all of whom were invited to comment on later stages of the work, informed the production of the report.

The input from a number of international experts in the USA, Canada, Australia and New Zealand is also presented.

The report ends with a discussion of how these issues may be taken forward.

3.6 How to Read the Report

The thematic chapters are the starting point for looking at the research evidence and other literature relating to each of the topics. Many of the findings, examples of good practice, and the methods, media and tools available apply to people in all the service user groups. Material relating specifically to a particular service user group or topic can be identified from the section headings in the text, and in the Table of Contents.

3.7 Exclusions and Omissions

We did not include the large body of literature relating to 'end of life' choices for people with dementia in this review, as we decided this fell outside our remit to consider choice in relation to mental health services.

We were unable to identify any literature on choice in relation to prisoners with mental health problems, nor anything specific to service users in forensic settings. Nor did we find much literature on choice for people with a dual diagnosis, or specifically relating to gay, lesbian and bisexual people, or on choice in relation to carers. This suggests these are areas where further research and publications would be welcome.

3.8 Terminology

We have, in general, used the terms 'service users', 'people with mental health problems', and 'people with learning difficulties' in reference to the position in the UK. This was because, from our contact with a range of voluntary sector agencies and user groups, and from published sources, we found these are the terms people receiving services most commonly say they prefer. When quoting specific legislation or guidance, or when mentioning specific services, other terms such as 'patients', 'people with mental illness', or 'people with learning disabilities' are used. In literature from other countries, terms such as 'consumers' are more commonly used.

3.9 Examples of Good Practice

We found examples of good practice in relation to many aspects of choice for different groups of service users. These are included in the chapters dealing with the specific topics to which they refer.

3.10 Methods, Tools and Media

Information on the use of methods, tools and media in relation to empowerment and choice is presented in this report. This includes written and pictorial material, and the use of other media such as audio and video tapes, CD-ROMs and DVDs, and internet web sites. There are also some examples of specific tool kits designed to facilitate choice on specific issues.

Communicating clear and accessible information to all groups of service users is crucial to facilitating choice. Some techniques, such as writing in plain English, and using appropriate pictures and symbols, will apply to the topics covered in many chapters of this report. There are also some general issues about using translation and interpreting services, and specific ways of communicating with people who have little or no speech, or who cannot hear. To avoid repetition, these are only included in Chapter 5.

4 The Nature of Choice and Empowerment

4.1 Summary of Key Points

- core principles for promoting choice for people in all client groups include acknowledging that people have the right to choose their treatment, and that choice applies across the spectrum of care;
- service user empowerment is a crucial first step towards enabling people to make choices about their health and other aspects of their lives;
- advocacy and support services can help service users exercise choice;
- new access points into mental health care should be developed, for example in libraries and walk-in centres;
- adequate resources and support are needed to ensure options are available to support individuals' choices;
- service users want better information on their options, using a variety of media, and access to self-management programmes, advance directives, direct payments and individual budgets;
- issues of inequality, which affect some groups, such as people from minority ethnic groups, and those with learning and communication difficulties, must be addressed;
- achieving service user empowerment and involvement requires adequate financial resources along with a positive commitment from professional groups, who must be prepared to give up some of their power.

4.2 Introduction

Core principles for promoting choice for people in all client groups include acknowledging that people have the right to choose their treatment, and that choice applies across the spectrum of care. To be able to make choices, service users need first to be empowered. There is a great deal of literature on service user empowerment, but we have included only that which specifically mentions this in relation to choice.

4.3 The Policy Context

The government's 2001 manifesto pledge to 'give patients more choice' was followed by a consultation exercise, *Developing Choice, Responsiveness and Equity in Health and Social Care*, to which a number of national expert task groups, including one on mental health, contributed (NIMHE, 2003a). This was followed by the Department of Health's response to the consultation, *Building on the Best. Choice, responsiveness and equity in the NHS* (DH, 2003b). Although this referred to giving people a bigger say in how they are treated, increasing choice of access to a wider range of services in primary care, where and how to get medication, book appointments and get

adequate and timely information, there were no specific recommendations relating to mental health services.

Choosing Health: making healthy choices easier had as its underpinning principles informed choice, tailoring support to meet individuals' needs and effective partnerships across communities (DH, 2004b). Improving mental health was one of six priorities.

Delivering Choosing Health: making healthier choices easier, the strategy for improving public health, included targets for reducing suicides, ensuring access to crisis services and CAMHS, 7 day follow up of people on enhanced CPA discharged from hospital, and improved access to services in rural areas (DH, 2005b). It emphasised the role of individual choice in relation to health and well-being.

Creating a Patient-led NHS. Delivering the NHS Improvement Plan focused on creating a patient-led NHS in which people have a greater range of choices and information, and NHS organisations which better understand patients and their needs (DH, 2005a).

Independence, Well-being and Choice. Our vision for the future of social care for adults in England outlined how services would help maintain individuals' independence by giving them greater control over the way in which their needs were met (DH, 2005c).

Although not specifically about choice, the Social Exclusion Unit's report described how people with mental health problems are socially excluded and the negative impact this has on individuals and society as a whole (SEU, 2004). Its action plan for improvement included addressing stigma and discrimination, and the role of health and social care services in tackling social exclusion for this client group.

The Care Services Improvement Partnership (CSIP) is the new umbrella body which includes the National Institute for Mental Health in England. CSIP drew up the *Our Choices in Mental Health Framework* as part of the operationalisation of *Building on the Best* (CSIP, 2005a). This includes four 'choice points': promoting and supporting life choices (e.g. work, education, leisure, housing, self-help, direct payments), access and engagement (choice of how to contact mental health services, including in an emergency, and the role of advance directives), assessment (choice of when and where assessments take place) and choice of service or treatment and care pathway. The accompanying *Choices Checklist* also identifies some examples of good practice (CSIP, 2005b).

Valuing People: A new strategy for learning disability for the 21st century provided the defining framework for developing learning disability services in England to ensure four key principles of rights, independence, choice and inclusion for service users (DH, 2001c). It focused on the provision of advocacy services, the extension of eligibility for direct payments, delivering a person-centred approach to care, and providing more support for carers. This strategy was informed by The Service Users Advisory Group whose report, *Nothing about us without us*, made specific reference

to the need for improved information for service users, access to direct payments and the ability to make life choices such as regarding housing options (DH, 2001e).

In Scotland, the first review of learning disability services for twenty years identified better information, communication and advocacy as central to improving services for this client group (Scottish Executive, 2000). As a result of this report, the Scottish Consortium for Learning Disability (SCLD) was set up in 2001 to offer training and support to bring about the recommended changes.

In Wales, a report by the Learning Disability Advisory Group identified a vision for how services should be in the year 2010 (Welsh Assembly, 2001). This included the statement that service users should 'have a right to make important decisions for themselves or with support if they need it', and urged that people with learning difficulties should have control over their lives through being able to exercise choice. The report also included a detailed action plan for improving services. The Welsh Assembly responded by publishing guidance on service principles and service responses (2004), which set out how the action plan would be implemented.

The Mental Capacity Act, passed by Parliament in April 2005, will come into effect in 2007 (Department for Constitutional Affairs, 2005). Applicable to anyone over the age of 16 in England or Wales, the Act includes key principles, including a presumption of mental capacity (i.e. the ability to make decisions for oneself), the importance of providing as much support as is needed to people to enable them to make their own decisions, and not treating someone as lacking capacity just because they make 'unwise' decisions. A lack of capacity must relate to some form of mental impairment, and must be specific to the particular decision that needs to be made.

In this respect the Act is very much in accordance with the patient choice agenda - someone with a learning difficulty who is being asked to consent to some form of treatment for example, should be given as much support and information to enable them to make the decision themselves. Even if they lack the capacity to make the decision, it should not be assumed that they cannot make decisions about other aspects of their care or treatment. The Act also provides several ways in a patient could make a choice about treatment prior to a loss of mental capacity, by making an advance refusal of treatment ('an advance directive'), in which they express their wishes and feelings, or a Lasting Power of Attorney, though only a valid and applicable refusal of treatment would be legally binding.

Choice is limited where someone is subject to the use of compulsory powers under the Mental Health Act as the Mental Capacity Act allows clinicians to override an advance refusal of treatment in these situations.

Although family and unpaid carers are not given additional powers of choice under the Act there is a legal requirement that they must be consulted about decisions for someone who lacks capacity, and in certain situations, where there are no family or unpaid carers, a professional advocate must be involved to represent the person in the decision-making process.

Ensuring that patients and people with disabilities, professionals and other paid health and social care staff, family and unpaid carers, are aware of the new Act and the rights, responsibilities and safeguards that it contains, will be a big challenge. The relationship with mental health legislation and how that will support, rather than reduce, choice could be particularly problematic, but at a wider level a crucial issue will be to ensure that the Act safeguards and promotes patient choice, rather than being inappropriately used to allow more power to be assumed by professionals and carers at the expense of patient choice.

4.4 Key Publications

People with mental health problems

Two recent publications have provided useful overviews of choice in relation to mental health. First, as part of a collaboration between the Institute for Public Policy Research and Rethink, Rankin's *A good choice for mental health* (2005a) comprehensively addressed the issue of choice for mental health service users. This included an overview of choice in the health service as a whole and in relation to mental health, describes the development of service user choice, and assesses the current availability of choices in a variety of treatment and life options. A number of core principles were identified for promoting choice in mental health and what is needed to support this in practice: 'in health and social care, people have the right to choose their treatment; choice is an aspect of a personalised responsive service; choice applies across the spectrum of mental health; choice can be expressed through individual and collective decisions; choice extends beyond health and social care'. The report recommended developing new access points into mental health services, via a range of services and workers, and introducing personal recovery budgets. Ensuring sufficient resources to provide service users with a range of options to choose from was seen as crucial. This would involve better commissioning, effective use of care plans, changes in the attitudes of professionals, support from professionals and advocates to support choice and information, and adequate resources to meet the need for a range of treatments including talking therapies.

Second, the Department of Health's Mental Health Task Group produced a detailed report (MHTG, 2003) in response to the Department of Health's consultation on *Developing choice, responsiveness and equity* (DH, 2003a). They examined the types of choice in mental health, and issues such as information, advocacy, empowerment and the 'expert patient', recommending better information for service users through multiple media, support in exercising choice, improved availability of self-management and recovery support programmes, and use of direct payments and advance directives. They also emphasised the need to address inequalities for people from Black and minority ethnic groups. In the context of access to services they called for multiple points of entry, lower waiting lists, training for GPs and A&E staff, and full implementation of early intervention services. They recommended ways to improve responses to service users experiencing a crisis, better access to talking treatments and a range of alternative therapies, and support to make informed choices about medication. Being able to choose a key worker and other professional workers, and the importance of therapeutic relationships, were emphasised. Recommendations were also made about access to social care

options and employment, ways of improving care in secure inpatient settings, raising staff awareness of the impact of alcohol and street drugs, and improving services' response to carers. They made a final call for mental health services in the future to be provided in radically different ways, focusing on a model of recovery rather than containment, underpinned by user research and user run services.

People with learning difficulties

Key publications on choice in relation to people with learning difficulties have come out of *Values into Action's* work on choice and control. *Who's in control?* looked at how people with learning difficulties make decisions, how organisations and other people can empower service users to make decisions, and legal issues. In each case, the report identified the support needed and the obstacles that have to be overcome (Edge, 2001). Core principles included recognising individuals' rights to make their own choices, the presumption that individuals have the capacity to make a decision unless proved otherwise, and the need to work in a person-centred way, and information is given on improving communication with people who find this difficult. Another VIA publication, *Making decisions*, highlighted best practice and new ideas for supporting people with high support needs to make decisions (Beamer & Brookes, 2001). Morgan's work on the *Choice Initiative* (2002b) included consideration of the communication needs of this service user group as an aid to empowerment and involvement. Stancliffe (2001) argued that the gap between this group's aspirations for self determination and the amount of control they actually have over their lives made this a crucial contemporary issue.

People from Black and minority ethnic groups

Best Practice in Mental Health: advocacy for African, Caribbean and South Asian Communities addressed the meaning of advocacy, self-help and empowerment for service users from Black and minority ethnic groups, and their application to these groups (Rai-Atkins *et al*, 2002). For example, they identified the need for advocacy services to align themselves with 'the values and beliefs of individuals within diverse cultural and social context', and a willingness to challenge the status quo of services predominantly commissioned and provided by white people. The report stressed the need to value diversity, and development of specialist advocacy services, as well as a supportive infrastructure for service users and carers, through the provision of adequate funding. They also highlighted the importance of providing linguistically diverse services, and culturally appropriate advocacy services.

4.5 Information from the Literature

The issue of choice is not entirely straightforward, and can be interpreted in various ways. The King's Fund has pointed out that the current political emphasis on health-related choice has been driven primarily by the need to meet targets and reduce waiting times in general hospitals, and that in some instances choice for some people will lead to inequity for others (Appleby *et al*, 2003). It has also argued that the choice agenda needs to encompass ideas of service user empowerment and the development of a more collaborative approach between them and professionals (Appleby & Dixon, 2004). Farrington-Douglas and Allen (2005) have pointed out that mental health service users are not currently included in the policies to extend

choice. It is essential that this group is empowered and supported to make decisions about treatment options, and also about services and service providers.

The Social Care Institute for Excellence's overview of social care development clearly set out the elements of choice: alternative services must be available, information must be accessible to service users, moving from one option to another must be possible 'and should not in itself be harmfully disruptive' (SCIE, 2005). Their report also made the point that service user involvement is not the same thing as consumerism, and that promoting service user involvement is necessary, but not sufficient, for promoting choice.

The Commission for Social Care Inspection's first report to Parliament on the state of social care in England highlighted the importance of improving the workforce in order to deliver person-centred services that offer choice and control to service users (CSCI, 2005). The report included key points on developing consultation and participation with service users, and on providing information to facilitate informed decision-making with people in all service user groups. It also states that 'choice is key to the future development of social care', that choices are only real if there is a range of good quality services available, and acknowledges that provision of services nationally to support individual choice is currently patchy.

Service user empowerment can be seen as a necessary first step to being able to exercise choice. By definition, as service users' power grows, that of others, such as mental health professionals, is likely to be reduced, a process that is not without difficulty in the context of the mental health system in England and Wales. The paradox of a system which promotes service user empowerment and choice, while 'simultaneously debating forced treatment in the community', has been discussed in relation to Canada (Clark and Krupa, 2002). It has also been pointed out that service users' increased involvement in the making of choices in recent years 'has not usually been matched by a greater range of choices' being made available to them (Campbell, 2001).

The Social Exclusion Unit described people with serious mental health problems as one of the most excluded groups in society, who had benefited least from initiatives designed to tackle disadvantage (SEU, 2004). Within their Action Plan for lessening social exclusion, they included 'people having genuine choices and a real say about what they do and the support they receive in order to fulfil their potential'.

The Mental Health Foundation has stated that individuals' mental well being itself has an impact on their ability to exercise choice, as do social, economic and environmental factors (Mental Health Foundation, 2005), and Rethink has called for people who are compulsorily detained to be given the same opportunity for choice as those who are not (Rethink, 2003).

Other commentators have discussed the extent to which exercising choice is a real option for people with mental health and other problems. Wareing and Newell (2002) argued from their work with people with learning difficulties in Australia that service users have, in effect, no choice, because choice has to be seen in the context of a society in which 'disablism' operates. In the UK, Richards (2004) put

forward the view that while the recent choice and self-help agendas can be seen as empowering for service users, they may actually be driven by a wish to transfer the economic burden of care from the state to the individual, a strategy which might also alleviate the current shortages of staff in many of the therapeutic professions. McIntosh (2003) argued that the actual process of observation and assessment limits individual service users' freedom and ability to make their own decisions, and can be seen as fundamentally connected to 'the process of diagnosis, classification and politicisation of the human conditions of old age and disability'. Lewis (2003) argued that the biggest challenge to making service user empowerment a reality was psychiatrists, who had yet to fully accept the new vision of shared decision-making.

Williamson (2004) reviewed the history and development of the service user movement. He concluded that, despite some shift towards involving service users at various organisational levels, individuals were still struggling to make choices about their own care and treatment. He suggested that positive government messages had not yet filtered down to service level. He identified the key barriers to service user involvement as a lack of information, the cost of meaningful involvement, the negative attitudes of professionals which marginalise and disempower service users and resistance to change. Rush (2004) also examined the history of the service user movement, and argued for open acknowledgement and resolution of the unresolved tensions between staff and service users, to enable meaningful service user involvement to take place. Similarly, researchers in Australia explored the concept of 'the politics of difference' in the context of the service user movement as a way of understanding the challenge mental health staff face in working collaboratively with service users (McAllister & Walsh, 2004).

Wallcraft (2003b) set out the key factors necessary for meaningful service user involvement, especially those who are hard to reach. These included proper resources, and support and empowerment by mental health professionals. NIMHE also suggested similar ways of overcoming the barriers, stressing the importance of a commitment to genuine partnership working between staff and service users (NIMHE, 2003c).

The Mental Health Act Commission recommended trust policies to support effective service user and carer involvement, the use of advocacy, and the provision of information and support, for example from PALS, to enable service users to make complaints or raise concerns (MHAC, 2003).

Linhorst and Eckert (2003) in the USA identified the elements needed for long-term service users to be empowered to make decisions about their personal care, and to contribute to the planning and development of services. These included: having structures and processes to support decision-making within a supportive organisational structure, and providing information, advocacy and support for service users. Finfgeld (2004) also examined the process of empowerment for people with mental health problems, and developed a nursing model to facilitate this. In the UK, Martin and Younger (2000) discussed how anti-oppressive practice could help empower people with dementia through communication and choice, using dementia care mapping as an assessment tool.

Harris (2003) presented an overview of current thinking on the concept of choice and how this related to empowering people with learning difficulties. He examined how staff behaviour and other social and environmental factors influence choice. He argued that choice is only meaningful if there are at least two options which would meet the individual's needs and concluded that choice is invariably a context-specific activity, and there needs to be a better understanding of how people can be supported in making important choices.

Jackson (2005) argued that the activities of the Disabled People's Direct Action Network (DAN) are likely to be counter-productive to enabling service user choice. A radical pressure group, DAN campaigns and promotes direct action to challenge the self-advocacy movement, established charities for people with learning difficulties and other disabilities, along with professionals and academics.

A systematic review of participation by mental health service users and people with learning difficulties in planning and developing social care services found that despite increased attempts to involve service users, individuals' exercise of choice remained limited, especially for people who were 'from a black or minority ethnic group, or are lesbian or gay' (Carr, 2004). People with learning difficulties and their carers from Black and minority ethnic groups face particular difficulties in becoming empowered and exercising choice, as many services have a values base which does not fit with their cultural and religious backgrounds (Mir & Nocon, 2002).

Some researchers have suggested that service providers may believe it is too difficult even to try to ascertain the preferences and choices of people with complex needs, including cognitive impairments and communication difficulties, effectively excluding them from involvement and choice (Clare and Cox, 2003; Fovargue *et al*, 2000). People with learning difficulties may be constrained in expressing choice by social and environmental influences, including the behaviour of professionals and carers (Harris, 2003), and those who also have a mental health problem may have particular difficulty articulating their views and making choices (Hebron, 2004; Lawton, 2002).

As well as individuals' difficulties in expressing choices, in practice the only choices available can be 'take it or leave it'; that is, to accept the service which is being offered or go without a service at all (Beamer & Brookes, 2001).

5 Treatment Choices

5.1 Summary of Key Points

- service users want to be offered more than just medication: they want access to talking therapies, services which take account of their gender, culture and ethnicity, and self-management programmes which are orientated towards recovery;
- when medication is the preferred option, service users want full information on its effects and side effects; they also want to be able to choose traditional medication in preference to atypicals, and to be given support when they choose to stop taking medication;
- service users in all client groups need information and support to help them make informed choices;
- carers for children and young people, people with learning difficulties, and older people with dementia need information and support to make decisions on the service user's behalf;
- there are some key points about good practice in communication in a variety of written and other media which apply generally to all service users groups, and particularly to those for whom communication is difficult;
- self-management programmes devised by the Mental Health Foundation, Rethink, and the Expert Patient Programme, all provide valuable information on how mental health service users can take an active part in working towards recovery;
- under the Department of Health's *Access, Booking and Choice* initiative, many mental health services have improved access and facilitated service user choice;
- The Mental Health Foundation and Values into Action are two of the organisations which have published information on how to help people with learning difficulties exercise choice.

5.2 Introduction

A number of issues related to treatment for people with mental health problems and those with learning difficulties are covered in this Chapter. For some service users, treatment is mainly, or solely, about medication, but there are a wide range of other possible therapeutic interventions. These include the 'talking treatments', encompassing individual and group psychotherapy, counselling, and other approaches such as cognitive behavioural therapy. There are also a number of self-management programmes. For some service users, making choices about aspects of their daily lives such as where and with whom they live, and how they spend their time, are crucial. This chapter also deals with the issue of capacity to make choices, and how this may be assessed.

5.3 The Policy Context

The Patient's Charter for England, introduced in the NHS in 1991, set out what patients had the right to expect from the health service. This was followed by a patient's charter for mental health services which included service users' rights to have their diagnosis explained, to be given information on the effects of medication and about alternative treatments, and to receive care in the least restrictive environment (NHS Executive, 1997). Service users were also entitled to information about advocacy and support groups, and to express a preference about the gender of their key worker. Although the national Patient's Charter was superseded in 2001 by *Your Guide to the NHS*, some Trusts, for example South London and Maudsley NHS Trust, have maintained and updated their Patient's Charter for people with mental health problems (Moran, 2005).

Comprehensive information on the evidence base for psychological therapies and counselling was aimed at providing guidelines for professionals in clinical practice (DH, 2001a). The report allowed for the guidelines to be adapted in light of local availability and organisation of local services, but said this should not be 'at the expense of changing the main recommendations', and urged service providers to ensure access to the range of therapies described. Despite a recommendation that the guidelines should be updated after three years, this has not been done.

The *Expert Patient Programme* was designed to enable people with long-term medical conditions to become actively involved in meeting their own needs, working in partnership with health and social care providers (DH, 2001b).

An *Access, Booking and Choice* programme in 2002-03 was facilitated by NIMHE, in partnership with the booking programme at the Modernisation Agency, aimed at improving access and choice for people with mental health problems or learning difficulties, subsequently publishing a report on the 140 teams who participated, representing 84% of all mental health trusts in England (NIMHE, 2003b). Improvements included the introduction of partial booking systems to give service users outpatient appointments at a time of their choosing, procedures for making follow-up appointments before the service user was discharged from hospital, improved referral processes between primary and secondary care services, and a reduction of the wait to see a mental health professional in A&E to a maximum of one hour.

Choose & Book: patients' choice of hospital & booked appointment gave people the right to choose between several different providers for some elective surgical procedures, and to go to another provider if the waiting list locally exceeds six months (DH, 2004a). However, a similar right does not yet extend to mental health service users who cannot choose between different providers of, for example, inpatient care or psychological therapies.

Contributors to the consultation *Developing Choice, Responsiveness and Equity in Health and Social Care* were asked what choices patients, service users and carers wanted, what information and support they needed to enable them to exercise choice, and what needed to change in the system and to working practices to support this (NIMHE, 2003a). The Mental Health Task Group's response to the

consultation included practical information on choice and responsiveness which would make most difference to service users, and advocated cultural changes in the way professionals work and systems are designed, including recommendations on information, advocacy and empowerment, access to services, options in a crisis, and choice of medication, other treatments, and professional workers (MHTG, 2003). The Department of Health's response to the consultation, *Building on the Best. Choice, responsiveness and equity in the NHS* (DH, 2003b), did not include the Mental Health Task Group's recommendations on extending choice in mental health services (Rankin, 2005b), and their conclusions were described as 'underwhelming' (Jackson, 2004b).

Choice in relation to treatment covers a wide range of topics, including preferences regarding medication, talking therapies and other treatments, access to a mental health professional of a specific gender and/or ethnic group, preferences for community or hospital-based care, and involvement in care planning and self-management. Because legislation includes the power to admit and treat people against their will, some mental health service users, unlike users of all other health services, do not have 'the absolute right to refuse treatment' (MHAC, 2003).

The National Service Framework for Children, Young People and Maternity Services includes a standard on the mental health and psychological well being of children and young people (DES & DH, 2004). Although this includes the requirement for a range of services to be provided to meet individual needs, it does not explicitly address the issue of choice for children and young people.

The Mental Health Foundation summarised the policy context within which the mental health needs of young people with learning difficulties can be met (MHF, 2002).

5.4 Information from the Literature

Treatment choices

Many commentators, including those from Rethink, The Sainsbury Centre for Mental Health, the Mental Health Foundation and The King's Fund have pointed out the impossibility of exercising choice when what people would like to choose is simply not available (George, 2004). Rethink's policy statement on choice in the treatment of severe mental illness argues that a lack of resources available for particular treatment options, such as the atypical antipsychotic medications, limits service users' freedom to make meaningful treatment choices (Took, 2001).

Service users most commonly say they want access to talking therapies, but waiting lists can be up to two years long (Rankin, 2005b). Guidance from the National Institute for Clinical Excellence on the treatment of depression recommended cognitive behavioural therapy (CBT) for people with mild depression (NICE, 2004). However, the availability of CBT is currently limited by a large shortfall in qualified therapists (Layard, 2004).

Some female service users would like to choose to be admitted to women-only units, and to be treated by female key workers and psychiatrists but, despite government

targets on women-only services, not all inpatient units can offer these. In a survey of women service users, many respondents felt that mental health services did not meet their needs, and were replicating inequalities within wider society. In many instances they felt unsafe in inpatient units (Williams *et al*, 2001). Others said they would like to have a choice of key worker (Forrest, 2004).

Most recently, respondents to a Rethink survey spoke about their vision of holistic mental health and personal care in which inpatient services are replaced with alternative provisions, such as crisis houses which could offer short-term sanctuary and stability (Faulkner & Williams, 2005). They also expressed a wish for drop-in centres of day services to be open round the clock so that information, support, advice and therapy was accessible at all times.

Where service users can choose between treatment options, positive outcomes are not always related to receiving their treatment of choice. A study comparing service users who chose cognitive therapy to treat panic attacks, with those who were randomised between cognitive therapy and antidepressant medication, found no difference in outcomes between the groups (Bakker *et al*, 2000). Other research compared individuals who had selected an Assertive Community Treatment programme from five treatment options, with others who had been assigned to it, finding only partial relationships between treatment choices and outcomes (Calsyn *et al*, 2000; Calsyn *et al*, 2003). A study in Norway found that when service users' choices about their own treatment programmes differed from the opinions of staff, the professionals' views tended to prevail, with staff more likely than service users to identify needs to do with professional monitoring and follow-up (Hansen *et al*, 2004). In some cases, service providers were resistant to changing their practice in order to offer service users more choice, even where this had been shown to have improved outcomes (Tsemberis *et al*, 2003).

Hope (2002), a psychiatrist writing about 'evidence-based patient choice and psychiatry' argued that 'genuine respect for patient choice is good in itself, even if it leads to poorer health'. Flynn *et al* (2003) argued that professional care givers should not assume that all health 'choices' are valid, or expect clients to live with the detrimental results of unwise decisions, as they have an overriding duty to safeguard clients' health. A review of the literature comparing staff and service users' views of treatment issues found that differences of views reflected the two groups' unique perspectives and preferences, rather than any decision-making deficit on the part of the service users (Roe *et al*, 2001). For example, the value systems and preferences of the two groups influenced the importance they placed on therapeutic and practical help, and on how they rated the effectiveness of inpatient care.

A study in the Netherlands compared the preferences for treatment during a first episode of psychosis among service users, their families and clinicians (de Haan *et al*, 2001). They found that service users and their families placed more importance on receiving early help in their home environment, and on creating a safe environment and a short waiting time before admission, than did the professionals, and service users valued low-dose medication more than the professionals. Service users and their families were most dissatisfied with the provision of information on diagnosis and medication. Researchers in Japan reported a gradual shift in attitude

as service users moved away from a passive role in their engagement with mental health services, towards a more participatory model (Slingsby, 2004). Although a similar attitudinal shift has taken place in New Zealand, more needs to be done to support service users' exercise of choice, and to ensure staff value users' views (Lammers & Happell, 2003).

Another author has addressed the issue of 'individual participation by service users in mental health care' in New Zealand (Read, 2003). He identified the need for staff to support individuals in finding their own definition of 'living well with mental illness', and helping them work towards achieving this. Recommendations to facilitate participation by service users included improving individual planning, giving better information on mental ill health and treatment options, staff training, peer support, and the availability of a range of treatment options.

Issues of choice and control in New Zealand were dealt with at some length by Goldsack *et al* (2005), who found that service users who received a recovery-orientated, home based acute mental health service were very positive, preferring this mode of care to hospital admission. This service combined the responsiveness, accessibility and flexibility of the crisis resolution model, with the recovery model's placing of the service user at the heart of the process and took a 'whole life approach' to dealing with the crisis in context. A study in Australia found that only half the carers of people who were treated by a domiciliary crisis assessment team preferred this community-based service to hospital admission (Fulford & Farhall, 2001).

Paulson *et al* (2002) argued for the need to use fidelity scales to measure and assure choice when assessing the impact of interventions for people with mental health problems, and described the use of such measures in a study of a supported employment service that incorporates choice as a key component.

Self-management programmes

Service users have argued for 'recovery-oriented services' which do not rely on coercion, disability, diagnosis and dependence, but are truly person-centred and empowering (Tenney, 2000), and for the provision of 'consumer-run' services which aimed to share power, responsibility and skills, and endorsed a non-hierarchical structure, and provided services in response to what service users said they wanted (Lunt, 2004; Resnick *et al*, 2004; Segal & Silverman, 2002; Segal *et al*, 2002; Szegedy-Maszak, 2002; Yanos *et al*, 2001). Other service users have reported wanting access to complementary therapies (Wallcraft, 2003a). Davidson (2005) has described the development of self-management approaches to mental health problems, influenced by the recovery model, including the *Strategies for Living Project* and the *Expert Patient Programme*, and several models of person centred planning.

The *Strategies for Living Project* built on earlier work by The Mental Health Foundation to identify what service users found useful when undergoing mental distress (Faulkner & Layzell, 2000). They reported on the helpfulness of personal relationships with friends, other people with similar problems, and professionals; medication, talking therapies and complementary treatments, exercise, interests and

activities. Some people found religious and spiritual beliefs made a big contribution to helping them deal with mental distress. Individuals also described their personal coping strategies for taking control and making choices. The subsequent MHF publication from this programme, *Something inside so strong*, included personal accounts by people who had developed individual strategies for overcoming their distress, along with a presentation of various strategies that were being taught or passed on to other people; the latter included the Manic Depression Fellowship's self-management training, and an approach developed by the Hearing Voices Network (Read, ed, 2001).

Rethink's *Self-Management Project* for people with a diagnosis of schizophrenia also puts service users at the centre of choice and decision making, and provides support for individuals to work towards their own recovery (Martyn 2002; 2003a; 2003b). The reports document the experiences of service users, and give examples of their strategies for maintaining morale and finding meaning, sustaining relationships with other people, having an 'ordinary life' (coping), having an 'extraordinary life' beyond coping, and managing 'having schizophrenia'. Rethink's recent survey found respondents continuing to support this approach (Faulkner & Williams, 2005).

The *Expert Patient Programme* (EPP) for people with some long-term health problems, including 'manic depression', is designed to empower service users to work in partnership with health and social care providers, and is mainly aimed at people with physical conditions (DH, 2001b). As part of the EPP in some areas, service users with a diagnosis of manic depression were offered a self-management training programme, devised by the Manic Depression Fellowship, to enable them to gain confidence in their own capabilities and take control of their lives. An evaluation of the EPP pilot sites in 62 Primary Care Trusts (PCTs) found that overall recruitment to the courses was low, with staff often unreceptive to the idea of user-led initiatives. It was recommended that the EPP be given a higher priority by PCTs in future (Kennedy *et al*, 2004). Other limitations were that the EPP was only delivered in English, staff lacked understanding and experience of working with mental health service users, and there was some evidence of discriminatory practices against people in this client group. A mixture of generic and disease-specific groups were offered, and no firm conclusions were reached about which might be more effective. The expert patient model has also been described as putting inappropriate pressure on some service users whose mental distress makes this a difficult role for them to embrace (Hopton & Nolan, 2003). Although the recent DH publication *Supporting people with long term conditions* makes no specific mention of people with mental health problems, it does reiterate that the EPP should be implemented in all PCTs by 2008 (DH, 2005e).

These models of self-management are similar to one described by mental health service users in new Zealand, which emphasised individuals leading their own recovery through taking 'personal power', while being supported by families and communities (Banks *et al*, 2004). Service users' self-determination, easy access to a broad range of services, and their lead role in developing national policy and planning local services were seen as crucial elements.

An assisted self-help programme for people with mild to moderate stress/anxiety was used in primary care with the aim of improving patient access and choice (Reeves & Stace, 2005). Although the number of recipients was small, most of them found helpful the assisted bibliotherapy, delivered in the non-stigmatising setting of GPs' surgeries, by non-mental health workers, and, when followed up after three months, were continuing to use the strategies they had learned. Bibliotherapy has also been reported in use in Cardiff, the Wirral and Kirklees (Mortimer, 2005).

A study in the USA found that when a primary care service to treat depression was modified in accordance with service users' expressed choices, uptake of treatment improved (Dwight-Johnson *et al*, 2001). However, these findings should be viewed with caution because the different health care system in America meant many of the subjects were excluded as they did not have the necessary health insurance. A study in Germany found that treatment choices that might be made by the general public were influenced by a general lack of knowledge and understanding of mental health problems and evidence-based treatment (Riedel-Heller *et al*, 2005).

Children and young people with mental health problems

Paul (2004) described the ethical issues involved in treating and providing choices to children and young people with mental health problems in the UK. He argued that it may not always be clear whether a duty of care is owed to the young person or to their carer, and explored to what extent the latter can act as a proxy decision-maker. He urged that, while complying with the requirements of the 1989 Children Act, practitioners should ensure young people are given 'the time, support and advice from their parents and health care professionals to assist them with decision-making'. Although minors have no statutory right to refuse treatment, in practice their wishes are only rarely overruled when it is felt to be in their best interests, such as when life-saving treatment for anorexia nervosa is administered. He urged that young people and their carers should jointly take decisions regarding treatment, with staff being honest about the circumstances in which their wishes could be disregarded, and the reasons for this.

Older people with mental health problems

Wetherell *et al* (2004) found that older people in primary care settings were less likely than younger people to seek treatment for mental health problems. Playford (2003) found many factors influencing older people's co-operation with care programmes, including their wish to have a wider and more flexible range of treatment options, including access to complementary therapies, urging a more user-centred approach to developing services for this group.

In some cases, it is carers' experience and views which influence the choice of service used (Claassen *et al*, 2000), and satisfaction with services (Kruzich *et al*, 2003). This is most often the case with people whose decision-making capacity is impaired by Alzheimer's disease (Hirschman *et al*, 2004; Karlawish *et al*, 2001), although some carers reported being given inadequate information and excluded from care planning (Dewar *et al*, 2002).

People with mental health problems, dual diagnosis, or substance misuse problems - life choices

Studies examining mental health service users' choice in regard to housing preferences have found a clear preference for independent living, rather than shared accommodation. They found the group home model of shared accommodation, devised for the resettlement of former long-stay patients in the 1980-1990s, stigmatising and inappropriate for their needs (Boyle & Jenkins, 2002; Warren & Bell, 2000).

Homeless people with a dual diagnosis of mental health and drug misuse problems had similar preferences (Schutt *et al*, 2005). Those who received housing without this being conditional on their acceptance of services for their mental health and substance misuse problems did as well as those who entered a treatment programme which required this commitment (Tsemberis *et al*, 2004).

Previous experience of services can also impact on service users' choices. Sosin and Grossman (2003) examined the choices made by homeless people with substance abuse problems, and concluded that service users considered the costs and benefits of service participation against alternative uses of their time and resources, in light of their personal perceptions of the services.

People with learning difficulties - treatment choices

The Learning Disability Task Force's report highlighted ongoing problems of implementing the *Valuing People* principles of rights, independence, choice and inclusion, and additional concerns that the Mental Incapacity Bill (now the Mental Capacity Act) might be used to stop people with learning difficulties from making their own decisions in future (Mendonça, 2004).

Cea and Fisher's study (2003) identified the ability of people with mild and moderate learning difficulties to make choices and give informed consent to a range of treatments, concluding that supportive decision-making or educational techniques could enhance this further. Stancliffe *et al* (2000) examined levels of personal control by people with learning difficulties with and without some form of substitute decision-maker or guardian, finding that those without guardians exercised a greater degree of personal control. Lawton (2002) studied the resources and support needed to help people with learning difficulties and mental health problems to be able to express choice, identifying barriers to their participation and recommending strategies to overcome these. The possible solutions included devising communication plans with details of individuals' non-verbal communication methods and needs, provision of training, support and supervision to enable staff to work in new ways, and the establishment of self-advocacy groups.

The Learning Disabilities Association of America's website (2005) emphasises the importance of allowing young people to make choices, giving tips for parents of young children in preventing mental health problems which include 'permit the individual to make his choices and to live with the consequences'. A guide for parents on 'taking charge of' their children's mental health stresses the choices available under the US system of care in terms of selecting service providers and treatment options (Allegheny County Department of Human Services, 2003).

People with learning difficulties - life choices

Although people with learning difficulties are sometimes assumed to be unable to articulate their housing preferences, some authors have argued that it is individuals' lack of knowledge of the available options which prevent them from exercising choice and that the barriers can be overcome (Bowey *et al*, 2005; Gorfin & McGlaughlin, 2003; McGlaughlin *et al*, 2004). Ways of helping young people with learning difficulties and communication problems to make choices and decisions at times of transitions, such as when leaving school, have been explored (Cameron & Murphy, 2002).

Other researchers have identified provider organisations' difficulties in getting service users' views on a range of issues from what they eat to whom they live with, urging that this should be taken more seriously, and that services should be required to demonstrate how they had arrived at choices on individuals' behalf (Joyce & Shuttleworth, 2001). A number of authors have identified ways in which people with learning difficulties can exercise choice in the basic areas of food and drink preferences (Hall *et al*, 2002; Keeton & Goodman, 2005). Feinberg and Whitlatch (2001; 2002) examined service users' ability to express preferences regarding personal care, and their choice of a family member to make some decisions on their behalf.

A study in Finland found disparities between the United Nations' rules on the human rights of people with disabilities, and the ability of people with learning difficulties to make choices concerning their everyday lives. It concluded that professionals must do more to promote service users' decision-making (Kjellberg, 2002).

Staff can be trained to improve their skills in providing service users with meaningful opportunities for exercising choice (Cooper & Browder, 2001). The Choice Initiative, run by the Foundation for People with Learning Difficulties, funded five projects in England aimed at supporting people to express their preferences and bring about changes in their lives (Wertheimer, 2000).

People from Black and minority ethnic groups - treatment choices

People from Black and minority ethnic groups were reported to have had particular difficulty accessing talking therapies (Keating *et al*, 2002), and Fernando (2005) stressed the need to ensure service users have the option to choose culturally appropriate services. Mind's survey of medication side effects found that people from Black and minority ethnic groups were given fewer treatment choices than other service users (Cobb *et al*, 2001).

Bhugra *et al* (2004) found that black patients in south London were less likely than white patients to come into mental health services via primary care, and that they experienced delays in accessing treatment as a result. They concluded that these factors contributed to black people coming into secondary mental health services through more coercive pathways, such as police referral, than white service users, and suggested that their dissatisfaction with primary care was also a factor. In a small study in Wales, Saltus-Blackwood and Kaur-Mann (2005) found that people from Black and minority ethnic groups were disadvantaged by assessment models

based on western understanding of mental ill health, and the lack of availability of treatments that acknowledged the importance of religious faith in service users' lives.

In America, Dupree *et al* (2005) reported that people from Black and minority ethnic groups tend to under-utilise outpatient services and become involved with inpatient mental health services when the problem has increased in severity. Their study found differences between the preferences of black and white service users for where services were delivered, and recommended that service providers should take into account service users' age, culture and ethnicity. Lasser *et al* (2002) found that black and Hispanic patients received about half as much outpatient mental health care as white patients, including mental health counselling and psychotherapy. A study in Singapore found differences in attitude towards mental health services by people from different ethnic groups (Ng *et al*, 2003).

Lesbian and gay people

Saulnier (2002) found that lesbians' choice of mental health services was influenced by the service providers' knowledge, sensitivity and attitudes towards gay people. The issues around supporting choice and control for gay and bisexual men with learning difficulties in Canada were described by Thompson (2003). This involved facilitating support groups about issues of sexuality in which the service users set the agenda for discussion, and enabling them to access mainstream services such as sex education and HIV programmes.

Service users subject to legal compulsion

The rights of service users who are compulsorily detained under the Mental Health Act 1983 to exercise choice have been strongly argued (MHAC, 2003; Took, 2001). In particular, that detained patients should have an input to planning their own care by means of the CPA, advance directives and crisis planning, and have their choice of key worker or other professional taken seriously. Perring *et al* (2004)'s study of how detained patients in Wales were able to express choice, found that access to therapeutic interventions was limited for those who were Welsh-speaking. A study in Finland found detained patients were prevented from making choices through ignorance of their rights to do so, highlighting the need for better information to be provided (Tuohimäki *et al*, 2001).

A small study of people detained under Section 37/41 of the Mental Health Act 1983, who were subject to additional legal restrictions, looked at their perceptions of leave, finding that having a choice about where to go when allowed out of the hospital was important to service users (Rees & Waters, 2003).

Choice in relation to compulsory treatment in the community has been examined in the UK, and in one province of New Zealand. A small study of service users in London found 60% of respondents would prefer to receive compulsory treatment in a community rather than a hospital setting (Crawford *et al*, 2004). Evidence from New Zealand suggests that service users felt generally positive about community treatment orders (CTOs), especially if hospital was the alternative, although the disadvantages included having less choice and more coercion in relation to medication, and a feeling of loss of freedom and being controlled by others (Gibbs *et al*, 2005). There were similar findings in relation to Maori people (Gibbs *et al*, 2004).

Dawson *et al* (2003) also described service users' ambivalence about CTOs and the paradox of some people who seemed to accept them as a form of advance directive for compulsory care.

Wheeler (2003) comprehensively reviewed the rights of people with learning difficulties in England who were subject to mental health legislation. Aimed primarily at guiding nursing practitioners through the decision-making process for this group of service users, he described the meaning of 'consent', of 'capacity to consent to treatment', and the definition of 'treatment' under the Mental Health Act. He also outlined the legal provisions underpinning treatment of consenting and non-consenting service users, whether they are detained or not.

Assessing capacity for choice

A number of instruments, of more use in research settings than in clinical practice, have been devised for measuring individuals' preferences and opportunities for exercising choice (Eisen *et al*, 2000; Hatton *et al*, 2004; Latvala *et al*, 2004; Townend & Shackley, 2002; Wills & Holmes-Rovner, 2003). Some studies have examined decision-making and choice by people with mental health problems who are receiving treatment for physical health problems, urging clinicians to understand and empathise with individuals' choices (Ness, 2002; Ranjith & Hotopf, 2004). Another approach to assessing decision-making capacity in older people used vignettes (Vellinga *et al*, 2005).

In a UK study of the capacity of individuals to make health care decisions, Wong *et al* (2000) found that while people with learning difficulties and dementia were less able than those in a general population control group, the decision-making capacity of people with mental health problems was no more impaired than that of the general population group. In contrast, another study found people in Singapore with a diagnosis of schizophrenia had impaired decision-making ability concerning compliance with medication (Wong *et al*, 2005). However, this interpretation is open to the criticism of such studies by Lawton-Smith (2002) that the service users involved were not asked for their views.

Ware (2004) discussed whether people with profound and multiple learning difficulties could be said to have views about complex conceptual issues such as future events. She discussed the use of proxies in decision-making, and considered the value of information obtained from assessments over time, in relation to ascertaining service users' preferences.

The issues of capacity and consent to treatment have been summarised to assist mental health nurses' continuing professional development (Dewing, 2001).

Medication choices

Service users have often reported wanting to be able to make a more informed choice over the medication they take, and its effects and side effects. A large community-based study in Scotland found nearly three quarters of respondents had not been given any choice in what was prescribed for them, and a third had received no information on their medication (Bradstreet, 2004). A study of long-term inpatients had similar findings, with few people realising they had any choice in the

matter of their medication (Billcliff *et al*, 2001). A study of acute admission wards found many inpatients had not been given information on the name and dose of their prescribed medication (Pollock *et al*, 2004). A survey in England by the National Schizophrenia Fellowship (now Rethink), Mind, and the Manic Depression Fellowship found two thirds of respondents had not been offered any choice of medication (Hogman & Sandamas, 2002).

Researchers in America reported a lack of information about whether, and to what extent, people with schizophrenia wanted to be involved in treatment decisions (Hamann *et al*, 2005). They concluded that if such individuals were involved in these decisions, it might improve compliance with the medication prescribed.

The Healthcare Commission's most recent survey of around 26,500 mental health service users found that less than half the respondents had definitely had a say in the medication they were prescribed, while two thirds of those who had been prescribed new medication had had this explained to them by a psychiatrist, and a third were given no information at all about possible side effects (HCC, 2005).

A small study of people with learning difficulties who were taking psychotropic medication found few service users were fully informed about their treatment, although most felt they had enough information (Heslop *et al*, 2005). Their carers felt uniformed about the medication, despite the service users' assumption that their carers would, or should, know all about it. Neither the individuals nor their carers were given enough information about alternatives to medication. Other authors have identified problems of people with learning difficulties being prescribed inappropriate psychotropic medication, and argued for better provision of information to them and their carers (Kroese & Holmes, 2005).

Some service users have chosen to continue taking conventional antipsychotic medication, rejecting the new atypicals for a variety of valid reasons (Abulseoud *et al*, 2002), while others have chosen to replace, or combine medication with alternative therapies (James, 2002). A number of researchers have found that NICE recommendations on prescribers and patients making joint choices about atypical antipsychotics are not always followed (Paton & Esop, 2005; Olofinjana & Taylor, 2005).

Service users wanting to stop taking medication reported a lack of information and support to help them do this (Read, 2005). This study of over 200 people by Mind found that 60% of respondents reported adverse side effects of their medication, including feeling sleepy all the time, and feeling 'controlled' by the drug. It also found that those who chose to stop taking medication against their doctors' advice were as likely to succeed in doing so as those whose doctors agreed, and that where doctors were involved, they were the group least likely to be found helpful, while counsellors, psychotherapists and other service users were most helpful. People who had been taking medication for a short time were more likely to succeed in coming off than those who had been taking it for more than five years. As well as support to come off medication, service users also wanted to be listened to and treated with respect, to be given alternatives to medication, and access to information and peer support.

The reasons why service users stop taking medication have received little attention from clinicians or researchers, although other commonly reported side effects include weight gain and loss of libido, along with the Parkinson's disease-like symptoms of stiffness and shaking, and the more severe and lasting tardive dyskinesia caused by some of the older anti-psychotic drugs (Cobb *et al*, 2001). As Lawton-Smith (2002) pointed out, a paper which examined 32 studies of 'non-adherence with antidepressant treatment' did not put forward any evidence that the individuals concerned had been asked for their views (Pampallona *et al*, 2002).

The position of the European Network of (ex-) Users and Survivors of Psychiatry on the involvement of service users in relation to psychiatric drugs was reported by Lehmann (2005). This concluded that they should be involved, as members of ethics committees and licensing bodies, in all issues concerning psychiatric drugs, including registration and monitoring, and providing guidance on decision-making about effectiveness. As a first step, independent and user-controlled research, education and information were proposed.

5.5 Examples of Good Practice

People with mental health problems

The NIMHE report on the *Access, Booking and Choice* programme gives details of the work done across the country by 140 teams working with people of all age groups who have mental health problems or learning difficulties (NIMHE, 2003b). These include a number of outpatient 'partial booking systems' to enable people to choose the time of their appointments, reducing the waiting lists for psychological therapies, and making user and carer involvement integral to the service.

The Mental Health Task Group response to the *Developing Choice, Responsiveness and Equity in Health and Social Care* consultation includes some examples of good practice aimed at ensuring service users can make informed choices about medication (MHTG, 2003). These include information provided by Mind and Rethink, and medication projects in South London & Maudsley NHS Trust and Norfolk and Waveney Mental Health Partnership NHS Trust.

Crouch (2003) described how a CPN in North East London Mental Health NHS Trust has developed comprehensive information packs for his clients, as a tool for helping them to make meaningful choices about the medication.

Strategies for Living includes examples of good practice in terms of service user-led strategies for coping with various aspects of mental distress - on-going survival strategies, crisis or life-saving strategies, symptom management, and healing strategies (Faulkner & Layzell, 2000). Relationships with friends and professionals, medication, exercise, religious and spiritual beliefs, money, hobbies and interests all play a part, as do personal strategies such as developing peace of mind and taking control.

Similarly, *Something Inside so Strong* includes individuals' accounts of their strategies for coping with mental distress (Read, ed, 2001). One person became a Mind volunteer as a way of developing self-confidence, while another became an

active partner in her own care, and a third substituted psychotropic medication with homoeopathy. The use of self-management programmes is also described.

Rethink's *Self Management Project's* reports give examples of several self-management initiatives (Martyn 2002; 2003a; 2000b). These include ways individuals can maintain morale and find meaning in life, getting support from family, friends, and other service users, and developing healthy living habits concerning diet and exercise. Being involved in work, recreational and social activities were also important, along with taking medication, accessing alternative therapies, and maintaining a relationship with mental health professionals, including managing symptoms and knowing what to do in a crisis. Rethink has also published a guide to antipsychotic and mood stabiliser medication which includes questions service users can ask their psychiatrist, information on side effects, and sources of additional help (Teasdale & Gilbert, 2004).

The ENeRGI (East Neuk Resource Group Initiative), described by Fox (2004), is a user-led service in Fife, Scotland, that provides drop-in housing support and volunteering services for people with mental health problems and their carers, guided by core values of service user choice and control.

The State Government of Victoria, Australia, has published a *Public Hospital Patient Charter* (2005), available in more than 15 languages, which sets out individuals' rights to be offered a range of treatment options, in a variety of settings, to be given information and to participate in planning their own care. Starting from the premise that services users are entitled to expect and receive high quality services in public hospitals, the charter promotes a partnership between them and health service staff.

The New York State Office of Mental Health's plan for mental health services (2004) includes a section on 'infusing recovery-based principles', which was drawn up by 'survivors, patients and ex-patients'. Its first rule for quality mental health services is that there must be informed choice. The other rules state that a service must be recovery focused, person-centred, knowledge-based, a system based on trust and partnership between consumer and provider. It should also do no harm, have free access to records and a focus on cultural values, and allow access regardless of ability to pay. The plan also proposes the development of instructional and/or collaborative tools that would help put these rules into practice, for example an interactive computer tool to help service users make informed treatment decisions. See <http://www.omh.state.ny.us/omhweb/statewideplan/2005/appendix4.htm>

Children and young people with mental health problems

Young Minds has published a guide to good practice in planning and providing mental health services for young people from Black and minority ethnic groups which includes the need to enable service users to choose whether or not to have a key worker of the same gender and from a similar cultural background (Kurtz *et al*, 2005). It is based on the underlying principles that services should be equitable, accessible, acceptable, appropriate, effective, ethical and efficient. It also deals with the issues of tackling discrimination. Examples of good practice identified include *Sharing Voices*, a voluntary sector project in Bradford aiming to improve links with the statutory sector and develop the capacity of voluntary organisations, featuring

befriending services, self-help and peer support groups, family work and support and faith-based support. Other examples are Bedfordshire's *campaign against living miserably (CALM)*, a project to tackle depression in young men, and projects in Croydon for young Asian women, African Caribbean families, and people from Black and minority ethnic groups more generally.

The National CAMHS Support Service web site includes a directory of good practice examples, some of which relate to choice issues. See http://www.camhs.org.uk/good_practice_see_all.asp

A 'CAMHS Choice and Partnership Approach' (C-CAPA), developed by two consultants in child psychiatry, has so far been used to train a number of CAMHS teams in England, and is due to be more widely adopted. The C-CAPA model puts service users and their families at the centre of all work, facilitating flexible, service user-led choice. A workbook is available to services which participate in this training programme (York & Kingsbury, 2005).

Under the US Medicaid system of funding for state and county run mental health services, parents of children with 'serious emotional disturbance' are able to choose between services provided in hospital or in the community, and to have a family care co-ordinator of their choice (Wyoming Mental Health Division, undated).

People with dual diagnosis

An anonymous example of an effective *Expert Patient Programme* for service users with mental health problems is given in the evaluation of the pilot sites (Kennedy *et al*, 2004). Three courses were completed, and the tutor used New Deal money to fund work with mental health and drugs teams to run one course for drug users.

A CPN in North East London Mental Health NHS Trust has devised a project to enable service users with mental health and substance misuse problems to articulate choice, where they are seen as the experts in their own care (Daniel, 2004). A collaborative project between a CMHT and a Drug and Alcohol Service, the *Friday Group* enables service users to build up their confidence through interaction within a peer group, and encourages individuals to make choices about healthier lifestyles.

People with learning difficulties

The Mental Health Foundation's *Choice Initiative* funded five projects to enable people with learning difficulties to make life choices (Morgan, 2000). These were: a job club, established as part of the Step Out Project in Liverpool; the Friendship Train in London, a project to encourage friendships among young people with high support needs; the Choices Project in London, which provided flexible activities in response to users' identified wishes; the Futures Project in London, which developed a 'communication passport' for young people preparing to leave school; and the Pathways to Citizen Advocacy project with the British Institute of Learning Difficulties, in which resource materials were developed for use by local advocacy groups.

A guide to help young people move on into adult life includes written information and a CD-ROM has been published by a development support group in Scotland (Outside the Box, undated). See <http://www.sclid.org.uk/pub/>

People from Black and minority ethnic groups

Rai-Atkins *et al* (2002) give examples of good practice in advocacy services to empower service users from African, Caribbean and South Asian communities. These include the *Mental Health Shop* in Leicester, which aims to empower black service users and carers to identify their needs and find ways to gain or regain control in meeting them, in which advocacy is a key component. Other examples are the *Buddies* group in Bradford, a user-led support scheme for black people, and the Somali mental health project in Sheffield, which provides a bridge between the community and the local mental health services.

5.6 Methods, Media and Tools

Key points on effective communication

In order to make choices, all groups of service users need information on the range of options available to them in terms of treatment and regarding other aspects of their lives. This information needs to be presented clearly, and in appropriate and accessible manner. This section deals with some key issues in communicating clearly with service users in order to facilitate choice.

Presenting written information in clear, jargon-free language is important for all groups, as is ensuring that written information, and that using other media, is translated into the languages appropriate for the local population. While services should be working towards providing a cultural diversity which reflects that of their clients, interpreting services should also be available where necessary.

Specific guidance is available on producing information for people with learning difficulties, including Mencap's guide to writing in an accessible way for people with learning difficulties (2002). This includes information on use of plain English, using layout and design to make the message clear, using images such as symbols, drawings and photographs. It also gives guidance on using other means of communication such as audio tapes, CDs and videos, and includes examples of good and bad practice in written materials, and sources of further information on accessible writing and images.

www.easyinfo.org.uk is a website about making information easier to understand for people with learning difficulties. The information was produced in collaboration with self advocacy groups and individuals with learning difficulties. It includes tools to make information easier to understand, information on good practice, and detailed guidance on issues such as information for people with visual impairment, people from Black and minority ethnic groups, effective use of pictures and symbols, and using methods such as video, audio and computers.

Some people with learning difficulties have no, or limited, speech. Talking Mats™ are an interactive resource which use picture symbols representing topics, options and emotions to build up an overall picture of individuals' and groups' views and

preferences. They have been successfully used by a number of services (Cameron & Murphy, 2002; Watson *et al*, 2003).

NIMHE's best practice guidance on mental health and deafness includes information on developing telemedicine to enable deaf service users access specialist consultation and advice (DH, 2005g). They also describe innovative work by the charity *SIGN*, which has developed software to interface with primary care computer systems to translate questions from service users, and the advice given by practitioners, using British Sign Language. They also recommend that mental health staff learn British Sign Language, and undergo deaf awareness training, and they also highlight the need for appropriate interpreters. They suggest the use of adapted telephones that use both voice and text, video equipment, and other devices to aid communication with deaf people.

Techniques also exist to enable children and young people to communicate their choices. The Commission for Social Care Inspection has described a variety of methods, media and tools used by National Children's Homes in their regular consultations with young people (CSCI, 2005). These include using games, talking to an adult one to one, magazines, newsletters, websites and text notes, and using poetry and rap songs.

People with mental health problems

The Mental Health Task Group (MHTG, 2003) and Rankin (2005a) recommended widening the access to mental health services, so that individuals did not have to go via their GP but could make contact through a range of non-stigmatising community-based services such as Children's centres, community centres, faith groups, public libraries, walk-in centres, and Accident & Emergency departments. Access should also be available via a broad range of access workers based in primary care and in voluntary sector agencies, and via telephone and Internet help lines such as NHS Direct.

Mind's *Making sense of coming off psychotropic drugs* answers some commonly asked questions about stopping medication, such as what to do if your GP is not in agreement, what is the best way to come off medication, what are the type of withdrawal effects you might expect and how to deal with them, and what sort of help might be available. It also includes information on useful organisations and websites to assist service users (Darton, 2005).

A website jointly run by South London and Maudsley NHS Trust, King's College London, Institute of Psychiatry, and Rethink provides information on mental health for friends, family and carers of people with mental health problems. This includes comparative information on different types of anti-psychotic medication, and other information which can assist with making choices. See <http://www.mentalhealthcare.org.uk/>

Aimed at service users and supported by the New Zealand Ministry of Health, an evidence-based resource about complementary and alternative medicine is available online at <http://www.cam.org.nz>

Also from New Zealand is a 'recovery resource for service users' which gives information on recovery and sets out how to get the most out of mental health services (Mental Health Commission, 2004). See http://www.mhc.govt.nz/publications/2004/Oranga_Ngakau.pdf

There is evidence from Australia that nurses have an important role to play in promoting self-determination in service users with schizophrenia (McCann & Clark, 2004). The promotion of wellness is partially achieved through a process of education aimed at increasing their clients' knowledge and understanding, and changing attitudes and behaviours that are not helpful to advancing their self-determination while reinforcing those that support it. The other component, fostering self-control, changes the balance of power between the nurse and service user, enabling the client to make decisions about their care and take control of their own well-being.

An American self-management tool, the Wellness Recovery Action Plan (WRAP) developed by Copeland (undated) can help service users develop their own recovery guide, and can also be used by staff who are helping them. In it, service users can record things they can do every day to keep them feeling well, triggers to and early warning signs of ill health, things which may avert a crisis, and what to do if a crisis occurs. See Copeland's *Guide to Developing a WRAP Wellness Recovery Action Plan* at the website of Healthy Place.com Depression Community - <http://www.healthyplace.com/communities/depression/mhrecovery/articles7.asp>

The Mental Health Association in New York State has set up a website to increase awareness of, and promote the use of, evidence-based practices in the State (2003). Available at <http://www.mhanys.org/ebpdb/index.htm> it enables people to search by key word, topic or name of service, and entries include information on the evidence for the type of treatment provided.

Children and young people with mental health problems

The Royal College of Psychiatrists publishes a number of leaflets aimed at children and young people of various ages, and their parents, including a *Checklist for Parents* to help them prepare for meeting their child's psychiatrist (Bamforth, 2005). They also produce *Changing Minds: Mental Health*, a CD-ROM designed for 13-17 year-olds, which includes a wide range of resources - audio, visual, video and written materials - and a wealth of references for further information and help on mental health for young people (Royal College of Psychiatrists, 2002).

People with learning difficulties

The Medication Matters team at the Norah Fry Research Centre, University of Bristol, have produced a checklist of things for people with learning difficulties and their carers to use to ask their doctor about medication (Heslop *et al*, 2005). They have also produced a booklet for service users to record information about their medication, a decision-making tool to help them make medication choices, and a guide to prescribers of psychotropic medication for people with learning difficulties. They stress that time needs to be spent explaining medication and other treatment alternatives to these service users and their carers, backed up with up-to-date and

accurate information tailored to individuals' needs, including the use of appropriate communication aids such as pictures and symbols, cartoons, video and audio tapes.

Housing Options has published information on how people with learning difficulties and their carers can get information and exercise choice regarding housing (King, 2003), and on a joint project to promote housing choice with Ealing Mencap and Notting Hill Home Ownership (Wood, 2001).

The work by *Values into Action* includes information on good practice in decision-making by people with learning difficulties, and how to support people to have choice and control over their care and treatment (Beamer & Brookes, 2001; Edge, 2001).

The Mental Health Foundation's *Choice Initiative* identified some key issues regarding communication about choice with people who have learning difficulties and high support needs (Morgan, 2002a). These include the need to take time to build relationships since communication is only effective in the context of knowing the individual well. Some people may only be able to express choices when they are in a particular situation, and their reactions may have to be interpreted. Intensive support and consistency are useful tools; friends, citizen advocates and professionals such as speech therapists can provide valuable support.

6 Choice in Care Planning

6.1 Summary of Key Points

- the Care Programme Approach (CPA) and Person Centred Planning (PCP) provide the frameworks for planning, delivering, monitoring and reviewing the care of people with mental health problems and learning difficulties;
- there is widespread agreement in the literature that mental health service users and their carers should be fully involved in CPA care planning, including in the assessment of risk; however, currently many service users and carers are not meaningfully involved;
- mental health service users who are involved in their own care planning are more satisfied with the services they receive than those who are not involved;
- The Royal College of Psychiatrists has published leaflets and checklists to help service users, psychiatrists and carers with the care planning process;
- people with learning difficulties and their carers should be fully involved in PCP as a way of supporting personal choice;
- as with other aspects of exercising choice, service users may need help with care planning from advocates or support workers;
- Valuing People has produced easily accessible information on PCP.

6.2 Introduction

The Care Programme Approach (CPA) and Person Centred Planning (PCP) provide the frameworks for planning, delivering, monitoring and reviewing the care of people with mental health problems and learning difficulties. In both systems, service users and their carers should be able to express their choices and preferences in terms of the types of care and interventions to be provided.

6.3 The Policy Context

The Care Programme Approach (CPA) was introduced in 1990 as the framework for the care for people with mental health needs in England (DH, 1990a), originally intended to be implemented by April 1991, running in tandem with the local authority care management system (DH, 1990b). The CPA was revised and integrated with care management in 1999 to form a single care co-ordination approach for adults of working age with mental health needs, to be used as the format for assessment, care planning and review of care by health and social care staff in all care settings (NHSE & SSI, 1999). The key elements are the systematic assessment of individuals' health and social care needs, the formulation of a care plan to address those needs, the appointment of a key worker to monitor the delivery of care, and the regular review and, when necessary, amendment of the care plan in line with the service user's changing needs. The importance of involving service users and their carers in drawing up CPA care plans was made explicit.

Subsequently, Standard 4 of the National Service Framework for Mental Health set out the requirement for service users to have a written copy of their CPA care plan. This should include the action to be taken in a crisis by service users themselves, their carers, and care co-ordinators. It should advise the GP how to respond if the service user needs additional help, and should be regularly reviewed by the care co-ordinator (DH, 1999).

As health care services within prisons are now provided by the NHS, prisoners with severe mental health problems come within the remit of the CPA.

Valuing People established 'a person-centred approach' to care planning for people with learning difficulties, as a mechanism for reflecting individuals' needs and preferences, and including issues such as housing, education, employment and leisure (DH, 2001c). Local frameworks to implement this were to be established by Learning Disability Partnership Boards. Service users would be offered a health facilitator to draw up a health action plan and support them in getting the health care they needed. Person-centred planning was intended to link effectively with care management, which was to remain the system through which health and social care was provided to this client group. Further guidance on person centred planning was produced for implementation groups, partnership boards, service users and carers, in which it was described as a process of continually listening to service users' choices, focussing on what is important to them now and in the future, and mobilising resources to enable them to pursue their aspirations (DH, 2001d). The Learning Disability Research Initiative was launched in 2002 by the Department of Health to conduct research into the policies set out in *Valuing People*.

Similarly, the Welsh strategy for people with learning difficulties put person centred planning at the heart of care provision (Welsh Assembly, 2004).

6.4 Information from the Literature

The CPA for people with mental health problems

The importance of involving service users in care planning and the whole CPA process is explicit. A recent review of the literature on the CPA found many examples of service user-led research, which has explored the extent to which the CPA has been implemented, and how involved service users were in the process (Warner, 2005). Findings suggested that service user involvement in the CPA was still not widely practised, although where service users were involved, they were happier with the services they received (Rose, 2003).

The Healthcare Commission's most recent survey of about 26,500 mental health service users suggested that involving service users in the CPA is still some way off universal implementation (HCC, 2005). They found that less than half the respondents had been meaningfully involved in drawing up their care plan, while a further third had had some involvement in doing so. Of the respondents on the enhanced level of CPA, indicating complexity of need and multi-agency involvement in care provision, less than three quarters had been offered or had received a copy of their care plan. Two thirds of the respondents felt they were definitely able to express their views at their review meeting. The survey measured the number of

people who knew who their care co-ordinator was (more than two thirds of respondents), but did not ask whether service users had had an opportunity to choose their care co-ordinator.

An overview of mental health services from a social care perspective between 2002 and 2004 included information from the Commission for Health Improvement's inspections of mental health trusts, highlighting different perceptions between the trusts and the service users of the degree to which individuals are involved in their own care planning (Robbins, 2004).

Carpenter *et al* (2004) conducted a large study in four districts in the north of England. They examined the extent to which the CPA and Care Management (CM) systems were integrated, and looked at nearly 300 service users' involvement in, and satisfaction with, their care planning. They found that most service users felt involved in planning their care and treatment, and that they had more choice when in the community, but this was less often the case when they were in hospital. Altogether less than half the service users thought they had a care plan, although there were differences between the districts ranging from more than a third to less than two thirds of service users. Those who had a care plan were generally positive about it, and nearly all knew who their key worker was. Service users in the two districts where CPA and CM had been integrated were more satisfied with services than those in the districts where the systems were separate. The authors concluded that service user involvement and choice are facilitated by the integration of health and social care.

Some authors have stressed the importance of involving service users in the assessment of risk, as part of their rights to autonomy and self-determination, arguing that their judgement is as valid as the professionals' (Hird & Cash, 2000). Others have described how service users' participation in treatment planning can be an empowering process in itself, once a number of barriers have been overcome (Linhorst *et al*, 2002).

Walker and Dewar's (2001) examination of carers' involvement in decision making for older people in a mental health respite and assessment unit found the majority were dissatisfied with their level of involvement, and identified hospital systems and processes, and the relationship between nursing staff and carers as the main obstacles to be overcome.

In relation to local authority care management, the Commission for Social Care Inspection found that the views of service users and carers were often not recorded in case files, making it 'difficult to judge whether they are empowered to make their views known' (CSCI, 2005).

Person-centred planning for people with learning difficulties

An evaluation of the impact of introducing person centred planning (PCP) was conducted as part of the Learning Disability Research Initiative (Robertson *et al*, 2005). This found that PCP led to improved life experiences for many service users in terms of their contact with friends and family, their community involvement, and in regard to choice. Other findings were that people with mental health, emotional or

behavioural problems were less likely to receive a plan, and to benefit from PCP if they had a plan, and that contextual factors also affected the benefits of PCP for some individuals. The role of facilitators also played an important part.

O'Brien's (2004) commentary on PCP emphasised its crucial role in supporting personal choice, and driving cultural change within the organisations providing services to people with learning difficulties. Nicoll and Flood (2005) discussed the processes involved in ensuring they can genuinely lead PCP, and what support is needed to enable them to do so. Llewellyn (2004) examined the advantages and disadvantages of nurses taking on the role of advocate in this context.

Rudkin and Rowe (2001) described the evolution of PCP, identifying several models of 'lifestyle' planning. They compared the outcomes for service users whose care was planned using Essential Lifestyle Planning, which focuses on positive factors, with those using Shared Action Planning, which takes a less explicitly person-centred approach. Their findings were, however, inconclusive. Other researchers identified some limitations to person-centred planning, suggesting alternative ways of eliciting service users' preferences might be more effective (Green *et al*, 2000).

Person-centred planning was implemented by a national voluntary organisation in its service provision for people with mental health problems, finding it an equally appropriate approach to meeting the needs of this client group (Parsons & Theobald, 2004). However, the authors caution against regarding PCP as a 'quick fix', emphasising the need for adequate staff training, building on current work practices, and recommend a gradual introduction for existing service users.

Carers of people with learning difficulties should be involved in the care planning process. Bungay and Alaszewski (2003) found carers were not adequately involved in initial assessments or other care planning, despite a local code of practice in working with carers. When possible conflicts of interest between service users and their carers were examined. It was found that in many cases the real conflicts were not within families, but between whole families and an inadequate care system, and recommendations were made for social services to provide better assessments of carers' needs as way of avoiding future conflicts (Williams & Robinson, 2001).

A training programme to help older people with learning difficulties take part in person centred planning was found to enhance their knowledge of and ability to exercise choice (Heller *et al*, 2000).

6.5 Examples of Good Practice

People with mental health problems

Perkins and Goddard (2004) have described how South West London and St George's Mental Health NHS Trust has improved service users' involvement in their own care planning. One key point, which was welcomed by service users, was the decision that all correspondence between professionals (e.g. mental health staff and GPs) must be copied to the person it referred to. The Trust also introduced the service user version of CUES (Carer and User Expectation of Services, Lelliott *et al*, 2001) which enabled individuals to describe their wishes and have them recorded.

This was coupled with staff training, jointly provided by service user and professional trainers, which covered not just the use of the instrument but broader issues of service user involvement.

People with learning difficulties

Howatson (2005) produced a detailed case study example of a health action plan for a person with learning difficulties. Comprising three sections, the first part provides a summary of the service user's healthcare needs and action to be taken to meet them. The second contains information on all outstanding issues for which actions had yet to be agreed, while the third part includes a detailed plan aimed at maintaining the client's mental and physical health and well-being. This example could serve as a teaching aid in person centred planning for clinical staff, and as a way to promote empowerment for people in this client group.

Easily accessible information on person-centred planning, aimed at people with learning difficulties, can be downloaded from the *Valuing People* website at www.valuingpeople.gov.uk This includes an explanation that person-centred planning is about listening to what service users want in their lives, and working jointly with them to decide what support they need to achieve their aims.

Derbyshire Mental Health Services NHS Trust's staff guide to writing care plans has a section on Health Action Plans to form part of person-centred planning for people with learning difficulties and mental health problems (Derbyshire MHST, undated). This plan should start with the wishes and aspirations of the service user and be jointly devised with their health facilitator, primary care nurses and GP. It should be designed to help the service user make and express choices about housing, education, support and leisure activities and include pictures as well as words.

6.6 Methods, Media and Tools

People with mental health problems

As part of its *Partners in Care* project, the Royal College of Psychiatrists has produced a number of guides aimed at helping service users, carers and psychiatrists to work in partnership. These are available as free leaflets, and can also be downloaded from the web site at www.partnersincare.co.uk. The checklist for service users lists questions an individual may want to ask their psychiatrist about their diagnosis, treatment and care, including what to do in an emergency and how to make a complaint (Timms, 2004b). Within the framework of information on confidentiality and sharing information (Allison *et al*, 2004), the checklist for psychiatrists (Timms, 2004c) and that for carers (Timms, 2004a), cover the questions that carers may ask psychiatrists about the service user they are concerned for, aiming to involve them as much as is possible.

An expert panel discussion in the USA covers the workforce issues that need to be tackled in preparation for a move to providing recovery-based mental health care (National Association of State Mental Health Program Directors, 2004). This includes information on staff training, and how service users can be involved in this. See http://www.nasmhpd.org/spec_e-report_fall04panel.cfm

People with learning difficulties

Parsons and Theobald (2004) described the model of person centred planning, and a number of tools to support its implementation:

- MAPS (Making Action Plans) - a collaborative group approach to helping an individual review their life experiences and aspirations, and plan to meet their goals;
- PATH (Planning Alternative Tomorrows with Hope) - a process starting with an individual's vision for the future and identifying what needs to be done to achieve it;
- PFP (Personal Futures Planning) - a strengths-based approach with ongoing support;
- ELP (Essential Lifestyle Planning) - which identifies positive and negative features of the individual's life and what support they need to enhance or eliminate them.

7 Choice in Service Planning and Delivery

7.1 Summary of Key Points

- involving service users in the process of service planning and delivery is not the same as enabling them to make choices about the services they would like to receive, but without involvement they can have no impact on the future direction of care provision;
- organisational culture and professional opposition often prevent service users from becoming fully involved in the planning, delivering and monitoring of mental health services, although there are some examples of where this is working well, and a range of materials designed to support service user involvement;
- certain groups of service users are particularly poorly involved in the service planning process;
- the impact of service user involvement in care planning and delivery is under-researched and under-evaluated. It is difficult to be sure to what extent service users' expressed choices actually lead to changes in services, although some examples of this can be found;
- having mental health service users as members of NHS Trust Boards, and involving them in staff selection, enables them to help shape the organisations which provide services; service user organisations can also have an impact on service development through influencing commissioning decisions;
- people with learning difficulties have been appointed as joint chairs to some of the local Partnership Boards, and ways have been found to enable service users to contribute to strategic planning;
- Young Minds has produced a guide to good practice in involving young people with mental health problems in planning the sort of services they would prefer to use;
- ways have also been found to involve people with dementia in staff selection and service commissioning.

7.2 Introduction

Involving service users in the process of service planning and delivery is not the same as enabling them to make choices about the services they would like to receive. However, if service users are involved in these processes their choices and preferences can have an impact on the future direction of care provision. We have therefore included literature identified in our searches that relates to this issue.

7.3 The Policy Context

The National Service Framework for Mental Health (DH, 1999) included service user and carer involvement as a core value, and the *NHS Plan* (DH, 2000) stated the importance of service users' involvement to improving health care provision.

Creating a Patient-led NHS. Delivering the NHS Improvement Plan described the intention to become 'truly patient-led', with NHS organisations becoming better at understanding patients and their needs (DH, 2005a).

The Commission for Patient and Public Involvement in Health (CPPIH) was established in 2003, funded by the Department of Health, with a remit to ensure the public was involved in decision-making about health and health services in England. In addition to the CPPIH's responses to national consultations, Patient and Public Involvement (PPI) Forums were set up in each of the 572 NHS trusts in England to influence local planning and provision of services.

As already described, *Valuing People* set out the framework for services for people with learning difficulties, including guidance on service user and carer involvement in planning and developing services (DH, 2001c).

7.4 Information from the Literature

People with mental health problems

A systematic review of the international literature found that involving service users in the planning and development of health care has contributed to changes in the provision of services across a range of different settings, with services accommodating some of the users' choices including: better provision of information, improved accessibility, initiatives to improve access to employment, crisis services, and complementary therapies (Crawford *et al*, 2002). Others have found, however, that real control and choice remains with service providers, rather than service users (Rutter *et al*, 2004), and that, rather than becoming involved with trying to change a service that does not meet their needs, service users may instead choose to dissociate themselves from it completely (Beresford & Hopton, 2000).

Rose *et al* (2004) systematically reviewed the literature on service user and carer involvement in change management in a mental health context and identified factors which helped and hindered it, and recommended user-led research to establish reliable outcome measures for this. An earlier overview of service user involvement nationally found that, despite some progress, there was evidence that good intentions were not being translated into reality in many instances (NIMHE, 2003c).

A national review of service user and carer involvement within NIMHE programmes of work found that some groups of service users had less involvement than others, implying that their choices were less likely to impact on service planning (NIMHE & HASCAS, 2005). These groups were: people from Black and minority ethnic groups; older people; younger people; gay, lesbian and bisexual people; people in rural communities; those using primary care mental health services; people with a diagnosis of personality disorder; prisoners and people in secure services.

The Commission for Patient and Public Involvement in Health is to be abolished, and the role of the PPI forums it established is changing. Some commentators have suggested that, as the new forums will be based in PCTs rather than specialist services such as mental health trusts, this will adversely affect the ability of members

to be involved in, and influence, mental health service planning and development (George, 2005).

In a study for the Social Care Institute for Excellence, Carr (2004) brought together the key themes from six reviews of the literature on the impact of participation, by all types of service user, on change and improvement in social care services. For all groups she found a lack of research, monitoring and evaluation on the impact and outcomes of service user participation in general, with agencies tending to focus on the intrinsic benefits of participation rather than on the change achieved by it.

Hopton and Nolan (2003) identified some inconsistencies between declared government intentions to involve service users in policy development and how this has been implemented, arguing for service users to be at the forefront of policy making, service planning and service delivery, informed by service user-conducted research. In contrast, Robert *et al* (2003) reported on examples of service user involvement in redesigning mental health services through a Mental Health Collaborative in one English region which eventually proved successful, once a number of setbacks had been overcome. For example, service users' views helped shape a review of the therapeutic activities available in one area, and changed practice regarding care planning and inpatient care, while staff reported they had gained new insights from having their views challenged.

Similarly, Perkins and Goddard (2004) described the evolution of a model of service user involvement in service planning, in which service users had input to the part of the organisation where the decisions were actually made, contributing to major strategic issues such as defining the directorate's clinical improvement targets. They identified the need to help in capacity-building for service users, and to involve people from Black and minority ethnic communities. Barnes *et al*, (1999) examined the conceptual issues relating to ideas of consumerism and choice, concluding that service user self-organisation should be encouraged and supported financially to redress the imbalance of power and ensure their meaningful contribution to service planning and delivery. Service users' contribution to making organisational change has also been reported from the USA (Genovich-Richards & Wyzkiewicz, 2002).

Robbins' overview of mental health services from a social care perspective (2004) described the Local Implementation Teams' (LIT) figures for service users' involvement as 'promising', with 60% reporting 'some systems for meaningfully involving service users in the planning and monitoring of services', while 40% reported 'effective structures' for involving 'a wide network of service users'. But Davidson and Vick (2002), reporting on the work of around 50 LITs in four English regions, found little evidence of mental health service users being put at the centre of the planning process, despite some examples of their involvement in local service commissioning, or as members of Trust Boards. Rae (2004) described how mental health services in Wales, where the requirement for service user participation was introduced later than in England, aim to involve service users in planning.

Evidence from one Australian state suggested that, despite raised expectations of service user and carer involvement in the design and delivery of mental health services, the extent to which this has been achieved varies considerably in different

areas, with carers least able to contribute to this (Lammers & Happell, 2004). Other Australian researchers examined how people with mental health problems engaged with consumer processes to influence policy and legislation (Bolzan & Gale, 2002).

Children and young people with mental health problems

An evaluation of 24 innovative CAMHS projects in the UK found young people valued the opportunity to be listened to (Kurtz & James, 2002). It recommended that all CAMHS should develop local arrangements for consulting with young people and their carers, and that their views should be taken into account in service planning.

People with learning difficulties

It has been argued that people with learning difficulties are insufficiently involved in strategic issues, and that more action is needed at the local level to support them in this (Glasby, 2002). Ward and Townsley (2005) presented an overview of issues and strategies for working in partnership with people with learning difficulties to provide information that is easy to understand. More information on this is provided at www.easyinfo.org.uk

Research by the Joseph Rowntree Foundation (2001) found that people with learning difficulties were involved to varying degrees in the early stages of decision making and participating on an equal footing with staff on boards and other groups, but more needed to be done to ensure their meaningful participation.

One element of service planning over which service users are starting to be able to exercise choice is that of selecting and training the staff who work in the field. People with learning difficulties were able to assist with selection of support staff in a NHS trust supported housing scheme (Walker & Duffy, 2001), employing a nurse in a trust's community team (Carlson, 2002), and choosing the manager of a learning disability service in a primary care trust (Last, 2003). All these accounts stressed the importance of service users' input being meaningful and not tokenistic. They gave examples of ways in which participation could be facilitated, such as the use of photographs and pictorial materials. Other authors discussed the advantages and difficulties of involving mental health service users in devising and delivering a pre-registration nursing curriculum (Forrest *et al*, 2000).

People from minority ethnic groups

People from traditionally marginalised groups face particular difficulties in contributing to service planning and, by implication, having their choices recognised. For example, Campbell *et al* (2004) identified obstacles to the involvement of African-Caribbean people in southern England which perpetuated existing inequalities and led to further disempowerment and disillusionment of service users. Distrust between the statutory and voluntary sector organisations, and their different understandings of the meaning of partnership, were severe impediments to service users' involvement, despite the expressed support of individuals' from both groups, and the 'cultural incompetence' of statutory services was also an obstacle. However, the authors caution against drawing too negative a conclusion, and urge that ways be found to overcome such difficulties. Ferns (2002) and Keating *et al* (2002) also identified that negative experiences of people from Black and minority ethnic groups further disempowers them in making a contribution to mental health services.

Older people with dementia

People with dementia have traditionally been excluded from making a contribution to service planning and development. Cantley *et al* (2005), as part of the *Involve People with Dementia Project*, explored how this group of service users might be involved, identifying examples of good practice, and testing out a number of approaches for involving them. They also identified the underlying principles of 'valuing personhood based on a holistic appreciation of, and respect for, the emotional, social, spiritual and artistic dimensions of the individual rather than a narrow focus on their cognitive abilities; valuing 'relationships' with people with dementia and recognising the importance of interdependence and reciprocity; and valuing citizenship and having a commitment to social inclusion based on securing people's rights, promoting ordinary living and ensuring that people are empowered and have as much choice as possible'.

Examples from general health care

Staff in other areas of health care appear to be grappling with the same issues as those working in the fields of mental health and learning difficulties. A report of the evaluation of a project to develop service user involvement in cancer services found some professionals were reluctant to extend this beyond making choices regarding their own care, despite the official view that they and their carers must be involved in developing cancer services (Avon, Somerset and Wiltshire cancer services network, 2003).

7.5 Examples of Good Practice

People with mental health problems

Mersey Care NHS Trust has a service user and carer on the Trust Board, and a policy of paying service users and carers for their involvement in a wide range of trust activities, supported by a realistic budget. Other trusts, including Derbyshire Mental Health Services NHS Trust, routinely include service users on interview panels when recruiting staff, and other examples are provided by NIMHE (NIMHE, 2003c). The voluntary organisation Together (formerly MACA), also involves service users in the recruitment of staff. See <http://www.together-uk.org>

South West London and St George's Mental Health NHS Trust has been one of the pioneers in employing service users in a range of its services, including clinical settings. Mersey Care NHS Trust has a similar policy about employing service users.

Rose *et al* (2004) identified a number of 'good practice points' which facilitate service user and carer in change management: having adequate resources, a facilitative organisational culture, good quality information strategy, autonomous service user groups, a professional champion, staff training provided by service users, training for service users, payment and/or employment of service users, representative structures, recognition and understanding of power differentials, acknowledgement of and sensitivity to factors pertaining to mental distress and practical measures in place to minimise these, such as advocacy service, and involvement processes which are high-quality, meaningful and measurable.

Carr's (2004) Position Paper for SCIE was intended to form the basis for practice guides on service user participation. It includes key messages for policy and practice, and includes the example of the Wiltshire and Swindon User Network (WSUN), a user-led organisation which has had a big impact on the empowerment of service users and helped them to make a contribution to local policy and service developments. WSUN is involved in influencing commissioning decisions, and in power-sharing in resource management through its control of the Wiltshire Independent Living Fund. It has developed user-controlled information and support services, and advocacy, and has had an input to the redesign of the care management processes and procedures, including staff retraining. It has also carried out a Best Value review on behalf of the local authority (JRF, 2002), and contributed to the formulation of good practice in this area (Evans *et al*, 2002).

Children and young people with mental health problems

Young Minds' guide for practitioners on ensuring participation by young service users (Street & Herts, 2005) describes how involvement, consultation and meaningful participation can have beneficial effects on the development of services, and includes examples of services where this has happened. Examples include a Barnardos participation worker, funded to work with the Leeds CAMHS, aiming to ensure that the views of young people and their carers are taken into account in service planning and development (Swales, 2005). In another example, the community adolescent service in Darlington has supported young people to identify the issues they think are important and begin a dialogue with service providers to take this forward.

Young Minds' guide to good practice in planning and providing mental health services for young people from Black and minority ethnic groups emphasises the importance of consulting with, and acting on the views of young people, and the need to offer a range of options from which they can choose (Kurtz *et al*, 2005).

People with learning difficulties

Several examples of good practice in local Partnership Boards, set up as part of implementing *Valuing People*, are given by Nicoll (2004). These include: appointing someone with learning difficulties as the joint chair of the partnership board in Poole, paying them the same rate as a member of an NHS board; meeting between self-advocates and supporters before and after partnership board meetings in Salford; a service user parliament in Cambridge, through which individuals can make their views known, which links with the partnership board; the use of video by the Bath partnership board to share information on its work with self-advocacy groups and others; self-advocate members of the Salford partnership board becoming paid council employees.

Gray and McAnespie (2004) described how people with learning difficulties were able to participate in service planning in East Lothian, Scotland, through taking part in a Best Value review. Starting with a conference for all stakeholders, including service users, the involvement programme included a number of focus groups for which people received detailed preparation, and at which attention was paid to facilitating communication by means of symbols. Service users felt they had been

meaningfully consulted and involved in this review, and the model was felt to be applicable for future consultations.

People with dementia

Cantley *et al* (2005) have identified the key stages in involving service users with dementia in planning and developing services, and provide detailed information for service providers including how to work with family members, ensure ethical practice, communicate with people with dementia, involve individuals as consultants or advisors, ensure good facilitation, and record views and action points. An example of good practice is the People Relying on People Group (PROP) in Doncaster, a group for young people with dementia which influences local practice in areas like care planning, selection of staff, and the commissioning and development of services.

The Commission for Social Care Inspection identified examples of good practice including a residential service in Islington which consulted people with dementia and their carers on the commissioning of new and more appropriate services (CSCI, 2005).

Good practice example from general health care

Avon, Somerset and Wiltshire cancer services (ASWCS) network has established a user involvement group which 'provides a supportive framework in which users are encouraged and enabled to effectively influence ASWCS in improving the provision, development and delivery of cancer services. The user involvement group is represented on a number of working groups within the ASWCS network, and is supported and informed by the publication of a regular newsletter. See <http://www.aswcs.nhs.uk/userinvolvement/index.htm>

7.6 Methods, Media and Tools

Children and young people with mental health problems

Young Minds' guide on participation includes tools that CAMHS can use to ensure participation by young service users, including a checklist of issues to consider and information on how to overcome potential barriers (Street & Herts, 2005). It also provides a list of further literature, tools, and other materials to help with involving young people. Some of these tools are not specific to children and young people with mental health problems, but have a broader relevance to involving people in this age group. Examples include:

- the *Headspace Project* in Somerset's self-advocacy and rights toolkit for young people who are inpatients in CAMHS, from <http://www.headspacetoolkit.org/>
- the Leeds participation project that gives young people and their carers a voice in how services are developed, interactive web site at <http://www.ru-ok.com/leeds.html>
- the *Ready Steady Change* project from the *Children's Rights Alliance for England*, including training and tools to put children's and young people's wishes, feelings and ideas at the centre of public services, from <http://www.crae.org.uk>
- Guides to consulting children and young people (Fajerman *et al*, 2001; Fajerman *et al*, 2005) from *Save the Children* at <http://www.savethechildren.org.uk>

8 Advance Directives and Advance Statements

8.1 Summary of Key Points

- mental health service users are keen to use advance directives and advance statements to make their wishes known, but they are only slowly being adopted in the UK;
- it is important that support is available to help service users draw up advance directives and advance statements;
- findings on their contribution to helping prevent emergency and compulsory admissions to hospital are so far inconclusive;
- some psychiatrists are unconvinced about the value of advance directives and advance statements, and some are reluctant to respect their validity;
- advance directives and advance statements can also be used by people with dementia;
- information and guidance on advance directives and advance statements is widely available.

8.2 Introduction

A number of terms are used to describe how individuals can plan in advance the type of care they would like, and would not like, to receive. The terms advance directives, advance statements, advance agreements, psychiatric advance directives (PAD), psychiatric wills, Ulysses contracts, joint crisis plans and crisis cards have all been used but are not synonymous. Such advance planning can include choosing both to opt in and to opt out of various forms of treatment. Thomas Szasz (1982) was an early proponent of mental health service users being able to use advance directives to refuse future psychiatric treatment, especially medication.

An advance statement is a statement of views or wishes to be taken into account in decision-making by those who are involved in providing care or treatment in the future. It enables someone to say in advance how they would like to be treated in a certain set of circumstances, for example in a situation when they were unable to communicate their wishes in other ways (Age Concern, 2003). An advance statement is not legally binding.

An advance directive, or living will, is intended to be 'a binding refusal of treatment', for example a wish not to undergo life-saving treatment under certain circumstances, or to refuse medication or ECT (Alzheimer's Society, 2002). An advance directive in which an individual chooses to 'opt in' to a specific treatment is known as a Ulysses contract (Atkinson, 2004). Although not supported by specific legislation, advance directives are likely to be legally binding under common law so long as certain conditions are met when they are drawn up (Parsons, 2000). There have been

some concerns that advance directives may restrict the clinical freedom of psychiatrists (Atkinson, 2004).

8.3 The Policy Context

The draft Mental Health Bill for England and Wales makes no specific reference to advance directives (DH, 2004e). This is in contrast to the situation in Scotland, where the Mental Health (Care and Treatment) (Scotland) Act, passed in 2003, became law in October 2005. The Scottish Act provides for advance statements to come into effect when an individual is to be detained or receive compulsory treatment; this must be taken into consideration by those responsible for their care but may be overruled by staff (Scottish Executive, 2005). The literature relating to mental health legislation in Scotland, including in relation to advance directives and statements, has been comprehensively reviewed (Atkinson *et al*, 2005). Atkinson and Garner (2002) also made the case for including advance statements in the new mental health legislation in England and Wales, arguing that it will be impossible to determine what is 'the least restrictive environment' in an individual case without knowing the service user's views and preferences.

The Making Decisions Alliance was unhappy that, although the draft Mental Incapacity Bill included references to advance directives, it did not mention advance statements (Department for Constitutional Affairs, 2003). They argued that including advance statements would enable individuals to express their preferences on a range of treatment and practical issues, and would also provide additional safeguards and direction for the person nominated to act on their behalf (MDA, 2003).

Building on the Best announced the development of 'HealthSpace', internet-based health record for every individual, as part of which people will be able to record their own notes on how they want to be treated, although it is not clear whether these notes will have the legal standing of an advance directive (DH, 2003b).

A commentary by Green (2000) sets the issues of capacity, choice and advance directives in the context of European human rights legislation, and summarises the Royal College of Nursing's professional advice on these issues.

8.4 Information from the Literature

Models of advance directives

Although advance directives are increasingly in use in the USA and UK, there is no single model (Atkinson *et al*, 2003b). The way in which advance directives are drawn up can vary from those which are completely or mainly service user-led, to others in which professional staff have a large input; the former type are most likely to promote individuals' autonomy and choice, while the latter may lead to improved communication between service users and staff (Atkinson *et al*, 2003a). One of the main benefits of drawing up advance statements or directives has been reported as being the negotiation between service users, carers and staff which strengthens the therapeutic alliance and improves care planning (Amering *et al*, 2005; Vuckovich, 2003). Advance directives have been in use in the USA for many years, with a

range of uses; at the most extreme end of the spectrum, they have been seen as a means to coerce service users to comply with treatment programmes (Monahan *et al*, 2003).

Evaluations of the use of advance directives

The experiences reported by one service user in England - although not necessarily representative - illustrated some positive and negative reactions to drawing up an advance directive (Dace, 2001). She was supported by her community-based consultant psychiatrist, CPN and GP, but when she was admitted to hospital her advance directive could not be accessed by ward nurses before drawing up a care plan, and the hospital-based consultant would not recognise the document. On a subsequent occasion, a respite admission was negotiated in a different ward, where the advance directive was seen by the clinical team as a helpful tool to assist with devising the care plan. This resulted in a better experience for the service user.

A randomised controlled trial (RCT) in London compared standard psychiatric care with the usual care plus the completion of an advance directive for mental health service users at the point of discharge from compulsory treatment, with the outcome measure being the rate of compulsory readmission (Papageorgiou *et al*, 2002). The researchers found no difference between the groups in the number of compulsory or voluntary readmissions, the number of days spent in hospital, or satisfaction with mental health services. The authors also reported that service users did not understand the importance of advance directives, and there was a lack of encouragement from staff. This led to recommendations that the right information needs to be given to service users at the right time, staff must endorse their use, continuity of care between inpatient and community services must be in place, and documents are legally binding so that service users will believe that their wishes will be respected (Papageorgiou *et al*, 2004). Another RCT in the south of England looked at whether advance directives could reduce the use of inpatient services and compulsory admissions. It found significantly reduced use of the Mental Health Act, and fewer admissions overall, for those who had advance directives (Henderson *et al*, 2004). However, Thomas & Cahill (2005) argued that that RCTs might not be the best way to evaluate the use of advance directives.

Srebnik and colleagues, researchers in Washington State, USA, have published extensively on advance directives. Considering psychiatric advance directives (PADs) as both 'prescriptive treatment preferences and proscriptive treatment refusals', they examined the attitudes of mental health staff towards them, and provided responses to the issues they raised (Srebnik & Brodoff, 2003). Their findings included staff concerns about how they would know a service user had made a PAD, whether users were sufficiently informed and competent to make one, and whether they could be overridden if they included treatment preferences which were not compatible with clinical standards of care. Staff also raised the issues of how much involvement they should have in helping service users draw up PADs, how the latter could be made to take account of changing circumstances, and whether a PAD was necessary when there was a clear 'crisis plan' in place. Others were also worried that service users' expectations might be unrealistically raised, as in practice not all their wishes might be carried out. They were concerned that existing forms were too complicated, that insufficient resources might constrain them

from complying with a PAD and that users might revoke it at a time of relapse, making it pointless. They were unsure if PADs were legally enforceable, and of their relationship to compulsory admission. They were also unclear about when PADs came into effect, about using them to consent to sharing of information, and about their own legal position if they complied with a PAD and there was an adverse outcome for the service user, or if they did not comply and the service user later complained.

Another study by Srebnik *et al* (2003) examined service users' interest in creating PADs, focusing on people at risk of psychiatric crises in which PADs might be used. They found service users were more interested in making PADs if they had support from their case manager, and their reasons included anticipating future mental health crises and wanting to make a plan to ensure they received their preferred treatment in these circumstances. Srebnik (2004) also looked at the benefits of PADs in terms of 'increasing choice and autonomy, promoting treatment involvement and dialogue, and improving crisis mental health treatment', considering evidence from the literature and data from an ongoing study. She concluded that when PADs were used during crises, the service users felt more empowered and positive about their treatment, family and clinician communication was improved, treatment was provided more rapidly and in a way consistent with users' preferences and escalation of symptoms and admission to hospital was often avoided. She also found that clinicians did not always have access to PADs during a crisis and concluded that initial difficulties would be overcome as PADs became more commonly used, and especially with the growth of leadership and values associated with service user choice and recovery.

PADs have been shown to be useful to people with all types of mental health difficulties. Peto *et al* (2004) studied need of service users with severe and persistent mental ill health for support to create PADs, using a computerised system, by means of an interactive workshop. They found that although service users needed varying degrees of technical help to use the computer, and of non-technical help such as explanations of the terminology and the use of PADs, from peer workers or case managers, all the participants were able to create PADs with help. To further address the issue of service users' ability to devise PADs, Srebnik *et al* (2004) devised a competence assessment tool, the CAT-PAD, for this purpose, suggesting that clinicians may take more seriously the PADs of service users who have been so assessed, which may make them more likely to honour the PADs.

Service users can communicate important information on their treatment preferences through the use of PADs. Srebnik *et al* (2005) conducted a systematic examination of the content and clinical utility of PADs created using the computerised system in their earlier study (Peto *et al*, 2004) which presented the user with questions about their preferences regarding psychotropic medications, hospital preferences, alternatives to hospital, emergency de-escalation methods including rank ordered procedures, and ECT. They were also asked about preferences in case of admission to hospital - who to notify if they were admitted, who was not permitted to visit them, what 'assistive devices' they needed to have with them (such as glasses and dental plates), dietary preferences, and who to contact regarding caring for dependants, pets and finances. The researchers found that the treatment

preference information contained in PADs was generally seen as clinically helpful to service users and psychiatrists in reaching agreed decisions on care, and might facilitate treatment consent and collaboration, expedite clinical care and avoid admission to hospital.

Geller (2000) examined the use of health care proxies in a Massachusetts state hospital, defining a proxy as an 'advance directive that allows an individual to indicate in writing who can act on his behalf when he lacks the capacity to make health care decisions', and what if any limitations there are on the proxy's authority. As the service user can revoke the proxy at any time, the researcher found little value in the role in relation to service users' admission to hospital, or consent to take medication, describing a complex system as only being further convoluted by the involvement of a proxy. He found only a small number of inpatients had a valid proxy, and argued that the 'purported benefits' of PADs had not risen beyond good intentions in the hospital under examination, and that empirical evidence was needed about whether they actually increased service users' autonomy.

Despite the wealth of evidence on PADs from Washington State, Joshi (2003) stated that they are only recognised in 14 US states, and identified difficulties in their use in connection with service users' legal capacity, problems of identifying an appropriate proxy when individuals are socially isolated, and a lack of awareness of PADs among some mental health staff. He also argued that it might be unethical for staff to be bound by a PAD when it was based on service users' past wishes, or when the service user rejected all forms of treatment or any family involvement in their care. However, Vuckovich (2003) disagreed with this assessment, stating that although there was specific legislation on PADs in only 12 American states, they were in use in all but nine of them, and argued that nurses had a crucial role to play in overcoming the barriers to their wider implementation.

Bell (2003) described the position regarding advance directives for people with mental health problems in New Zealand, which is broadly similar to that in the UK and USA. She also made the point that they may differ from advance directives for people with physical illnesses as they are likely to be for limited, if cyclical, periods of time, and to be informed by individuals' previous experiences of treatment.

Ethical issues relating to psychiatric advance directives have been examined by researchers in The Netherlands (Widdershoven & Berghmans, 2001a) and Germany (Sass, 2003), using narrative methods and discussed in terms of the values underpinning them. Appelbaum (2004) reviewed how the outcome of a legal case in Vermont, USA, which found that people admitted compulsorily could not be excluded from the coverage of PADs, may inhibit clinicians from supporting service users in making them.

Advance directives for people with dementia

There is a body of literature relating to the use of advance directives by people with dementia. Holm (2001) examined the extent to which people with dementia could be regarded as being competent to make advance directives, and concluded that their presence did not relieve the caregiver of an obligation to assess the service user's decisions and 'ethically choose which to respect and which to counteract'. Other

authors also considered the ethical issues and concurred with Holm (Widdershoven & Berghmans, 2001b). Similarly, Mezey *et al* (2000) agreed with Holm that individuals' decision-making capacity is on a continuum, rather than being simply 'present' or 'absent', arguing that assessments of capacity must be linked to the specific activity - such as appointing a proxy, or refusing a specific treatment - which is being considered.

In view of people with dementia's progressive lack of cognitive functioning, Rempusheski and Hurley (2000) recommended discussing advance directives as soon after diagnosis as possible with the service user and their family. They argued that nurses' detailed knowledge of the individual is crucial in deciding when to implement previous requests. While agreeing that nurses play a pivotal role with this group of service users, Moody (2003) argued that they must use advance directives ethically, respecting the individual's 'personhood'.

Williams and Rigby (2004) examined the use of advance statements with older people with dementia and those with functional illnesses, identifying benefits to their use for both groups. They reported that, as many people with dementia are now seeking help at an earlier than previously, there were more opportunities for using advance statements and directives with this group. Despite also identifying some limitations, and concerns about the possibility of overriding individuals' wishes under the provision of the Mental Health Act, they conclude that advance statements give clinicians the opportunity to help service users make their own decisions and plan for the future.

8.5 Examples of Good Practice

People with mental health problems

Derbyshire Mental Health Services NHS Trust has produced an *Advance Directives Policy* aimed at staff (Hopkinson, 2003), and *Guidelines for people making an Advance Directive* for service users (Derbyshire MHST, 2004). These cover an explanation of the legal context and current good practice, and enable service users to state how they would like to be treated on future occasions, and to specify services or treatments they do not want to receive.

Similar guidelines on making advance directives have been produced by Hertfordshire Partnership NHS Trust (undated), South Essex Partnership NHS Trust (Waddington, 2005), and jointly by the NHS trusts and local authorities in Kent and Medway (Kent and Medway NHS, undated).

Mersey Care NHS Trust has introduced advance statements for its mental health service users, which include their preferences about medication, financial matters, and arrangements for taking care of their children, home and pets.

Older people with dementia

The creation of a care pathway for people with dementia in a NHS continuing care unit for older people with mental health needs has been described from the points of view of the clinical manager and a service user with dementia (Ashley & Schofield, 2002). This ensures that users' preferences are recorded on a wide range of

lifestyle issues and treatment options at an early stage, enabling these to be carried out when they lose the capacity to make their wishes known. Issues covered by the plan include sleeping and eating habits, preferred term of address, choice of leisure pursuits, clothing preferences, toileting requirements, issues about sexuality, desire for solitude or company, and attitudes of others.

8.6 Methods, Media and Tools

People with mental health problems

Several voluntary organisations have produced clear fact sheets for service users about advance statements, which are available in paper form and free to download from the Internet (Age Concern, 2003; Alzheimer's Society, 2002; Beever, 2002; Mind, 2005; Rethink, 2002).

The Scottish Executive has published a guide to advance statements in the context of the new Mental Health Act which includes answers to frequently asked questions, information on sources of help and support, and a suggested proforma (Scottish Executive, 2005). This includes space for service users to record their treatment preferences and specify any treatment they do not want to receive.

There are many examples of guidance on making advance directives in the USA, including sample proformas, including those published by the Bazelon Center for Mental Health Law (2003), and Duke University (undated). Although tailored for a different legal system, the general principles and issues covered are relevant for the UK situation and similar to many of those produced in the UK. Similarly, a leaflet from New Zealand explains how service users can use advance directives to make their treatment choices known (Mental Health Commission & Health and Disability Commissioner, 2003).

The National Mental Health Association in the USA has produced a toolkit for making advance directives (2005). This includes a discussion of the issues, information on legal considerations, a training module for staff, a practice worksheet and a glossary of terms used. See <http://www.nmha.org/position/advancedirectives/index.cfm>

9 Direct Payments

9.1 Summary of Key Points

- direct payments are paid to an individual by local authority social services departments as an alternative, or in addition to, direct service provision, with the aim of improving recipients' quality of life.
- recipients can use the payments for a wide range of services, and can choose to buy personal support and respite care or to access leisure, education and social opportunities.
- they are available to people with mental health problems, and those with learning difficulties, in all age groups.
- uptake of direct payments nationally for people with mental health problems or learning difficulties has been slow, despite local authorities having a duty to offer them to service users, and a number of initiatives to promote their use;
- staff in some services are not yet committed to supporting service users in using direct payments;
- support in arranging and managing direct payments is crucial for service users;
- Service users who have been supported to make use of direct payments have been very satisfied with this tool to increase their choice of care provider;
- direct payments are of limited use if there is not a local choice of service providers;
- reservations have been expressed about the potential risk for service users employing untrained or unsupervised staff, and the problems service users may have in managing budgets, though this could be overcome by providing formal support, or managing agents or brokers;
- the experience of service users receiving direct payments appears to be positive, with an increase in independence and choice cited.

9.2 Introduction

Direct payments are paid to an individual by local authority social services departments as an alternative, or in addition to, direct service provision, with the aim of improving recipients' quality of life. Recipients can use the payments for a wide range of services, and can choose to buy personal support and respite care or to access leisure, education and social opportunities. They are available to people with mental health problems, and those with learning difficulties, in all age groups.

9.3 The Policy Context

The *Community Care (Direct Payments) Act 1996* came into effect in England in 1997, making it possible for local authorities to make direct payments to people assessed as needing community care services. From 2003, the implementation of

Sections 57 and 58 of the *Health and Social Care Act 2001* imposed a duty on local authorities to offer direct payments to those eligible. The new regulations also removed the previous ban on making payments to partners, parents or other relatives, and local authorities must be satisfied that recipients consent to receive direct payments, and have the mental capacity to manage them either by themselves or with support (Dow, 2004).

Valuing People, the government's strategy for learning disability in the 21st century, described direct payments as an effective means of helping people gain greater control over their lives, and stressed that good support was needed for this policy to be implemented (DH, 2001c). Similarly, the option of direct payments for service users in Wales was included in the Welsh Assembly's *Guidance on service principles and service responses* (2004).

The assessment of the *National Service Framework for Mental Health - Five Years On* accepted that take up of direct payments had been low (DH, 2004f). The Green Paper *Independence, Well-being and Choice* set out the government's 'vision for the future of social care for adults in England'; one chapter described the process of putting people in control by, among other strategies, improving the take-up of direct payments (DH, 2005c). To overcome some of the problems reported with direct payments, such as the complex administrative arrangements needed for a service user to directly employ care and support staff, it proposed the development of individual budgets, managed by the local authority on behalf of the service user. It also proposed changing the name of direct payments and suggested a number of possible alternatives.

In their response to the Green Paper, the Social Care Institute for Excellence recommended that an improvement in uptake could be achieved by reducing the bureaucracy and delays associated with direct payments, creating better links with the benefits system, and recognising that service users need to be able to offer an appropriate hourly rate to staff they employ (Carr, 2005). They also advocated providing more information on the scheme for service users, and for social care staff, and better funding for independent advocacy services. They felt that social care services would need to be prepared and resourced for a change in culture and working practices, and argued for health care services to be included in the system in recognition of the fact that much care, such as that in mental health, is now jointly provided.

In their response to the green paper, the Mental Health Act Commission made some practical suggestions about simplifying the application process, providing better information and, for detained patients, building direct payments into Care Programme Approach and Section 117 discharge planning (MHAC, 2005). They also urged piloting the various options for direct payments and personal budgets, advocating a clear structure with inbuilt safeguards for service users and the staff they employ.

The *In Control* project's response to the Green Paper strongly supported the use of individual budgets for people with learning difficulties, but included a number of concerns about how this might be made to work in practice (Duffy, 2005d). These

related to making changes to the overarching economic framework, putting individual budgets into the context of self-directed support, changing policy regulations for care management, assessment and commissioning of services, and ensuring the public better understands our common rights and responsibilities.

The Department of Health's *Responses to the consultation on adult social care in England* reported broad support for promoting and further extending direct payments, especially from service users and organisations representing them (DH, 2005d). However, concerns were raised that individuals employing personal assistants (PAs) might be at risk unless care staff were required to have Criminal Records Bureau (CRB) and Protection of Vulnerable Adults (POVA) checks prior to employment. There were also worries about risks to staff potentially working without training or supervision. The difficulties of employing suitable staff on the comparatively low rates of pay offered were highlighted, and concerns expressed that direct payments were being used as a way of driving down the overall value of care packages. Some respondents, especially social care staff, expressed reservations about direct payments in some circumstances for people with mental health problems, those with learning difficulties, and older people, and in general it was felt that older people might find direct payments more of a burden than a help. There was strong backing for the need for better support for service users, and the provision of comprehensive and timely information. There was also support for extending the scope of direct payments to include other services, including those provided by local authorities, and to extend it to groups who are currently ineligible. Carers expressed concerns that managing direct payments might be added to their existing burden of care, and supported the idea of agents and brokers to manage individual budgets. The potential of direct payments and individual budgets to destabilise existing care markets was raised by some respondents, and some individuals pointed out that direct payments were of no use to them if the service they wanted to purchase was not available locally.

It was announced at the end of 2005 that a home care allowance scheme is to be piloted in 13 areas of England from 2006 (DH, 2005f). A variety of models, through which service users from all client groups can use their personal care budgets to buy social care, will be assessed before the scheme is extended nationwide over the next seven years. Funding for the scheme has been brought together from the Department of Health, the Department of Work and Pensions, and the Office of the Deputy Prime Minister.

9.4 Information from the Literature

Projects to encourage uptake of direct payments

An evaluation of the national direct payments pilot scheme took place from 2001 to 2003 (Spandler & Vick, 2004). The study aims included identifying the range and variable use of direct payments, providing 'real life' examples, comparing the approaches to implementation across the five pilot sites, highlighting the factors helping or hindering their take-up, exploring the process and impact of direct payments on service users, exploring the benefits and difficulties from using direct payments, and analysing the findings within the context of national and local policies and published literature. The small sample of recipients reported direct payments

having a positive impact on their quality of life, giving them better access to a wide range of social and leisure activities, as well as physical exercise and educational opportunities. Individuals reported increased feelings of self-worth and independence, better social networks, and an overall benefit to their mental health as a whole. Having more personal autonomy, choice and control were also reported, as were improved self-esteem and assertiveness. By accessing mainstream services, individuals felt less stigmatised and more socially included, and some felt direct payments were supporting their path to recovery. Although no systematic evaluation of hospital use was undertaken, there was some anecdotal evidence that, for some people, mental health crises could now be managed in a different way, which did not involve an admission to hospital, and that in some instances where admission was inevitable this might be arranged informally rather than compulsorily.

The authors of the HASCAS evaluation also reported in more detail on the crucial role of care co-ordinators in enabling their clients to access the direct payments to which they are entitled, noting that a radical re-appraisal of their roles, responsibilities and practices is needed (Spandler & Vick, 2005).

HASCAS also carried out a content analysis of direct payment policies in England in which 96 local authority policies were assessed against a coding frame developed through consultation with the Department of Health and informed by current legislation and policies (Tobin & Vick, 2004). Around three quarters of the policies were reasonably comprehensive in content and written in an accessible style. There was a fair degree of congruence between them, with most policies emphasising user empowerment and promoting independent living. However, many policies had not been revised in light of recent national guidance regarding eligible client groups and the range of allowable uses for payments. Although most policies mentioned regular financial monitoring arrangements, few included service user involvement in monitoring and quality assurance, and there was little mention of advocacy services or promoting direct payments; in particular, there was insufficient promotion to people from BME communities. Recommendations were made for local authorities to improve the context and content of their direct payment policies, and for this to be regularly monitored.

The *New Directions* project, described by Newbigging & Lowe (2005) 'set out to engage with service users and professionals to raise awareness about direct payments and their potential for people experiencing mental distress, particularly those from Black and minority ethnic communities' by means of a series of focus groups and a national event. Their key messages included the need for service users to have easy access to an assessment of their needs, for staff and applicants to have good access to information on direct payments and how they can be used, for mental health advocacy and support to be provided, and for the paperwork to be simplified and aligned with the Care Programme Approach. Outreach and support services should be provided to ensure increased take-up from people from BME groups. Mental health services need to undergo a cultural shift to ensure a commitment to service users' self-determination and their increased exercise choice and control in their lives. National and local leadership are needed to assist with the implementation of the scheme, and the development of partnerships, and inter-agency collaboration are essential. The impact of direct payments on the overall

system of service commissioning must be considered, and what can be funded through the scheme should be reviewed to acknowledge that it is not always possible or relevant to make a distinction between health and social care in mental health. The Joseph Rowntree Foundation (2005) also identified ten key points on implementing direct payments, based on this project. These included the provision of accurate and accessible information, advocacy and practical support for service users, approaches to reach people from BME groups, and a change in the culture of mental health services with staff promoting self-determination among their clients.

A recent qualitative study of public views relating to choice in health care in general found varying responses to the idea of direct payments, with respondents expressing concerns about 'the complexity of decisions and the information that would be required' (Rosen *et al*, 2005). Although participants included some people with long-term conditions, and some carers, it is not known whether any had themselves used direct payments.

Barriers to uptake of direct payments

The Commission for Social Care Inspection examined the barriers to uptake of direct payments in England, finding fewer than 13,000 people altogether were using them, of whom 229 had mental health problems and 1,337 had learning difficulties (CSCI, 2004). Barriers to uptake included a lack of clear information for service users, professionals' lack of awareness of the scheme and their restrictive or patronising attitudes towards service users taking more control, excessive bureaucratic paperwork, inconsistent local interpretation of national guidelines, and several difficulties associated with employing personal assistants. Their recommendations to improve uptake included providing better information to all parties, along with training for staff, better access to advocacy and support services for applicants, and a cultural change in health and social services to support service users' self-determination. Their findings and recommendations largely echoed those of Spandler and Vick (2004).

A study by The Scottish Executive explored the factors inhibiting direct payments to people in Scotland, and ways in which their provision could be encouraged (Ridley & Jones, 2002). As in England, take up had been slow, although service users were generally enthusiastic when told about the scheme. Their most commonly reported concern was having to manage the financial arrangements, as many people were unaware they could use a support agency, rather than directly employing personal assistants. Staff were worried about the possibilities of fraud and exploitation. The negative views expressed did not reflect those in a previous study of direct payment recipients in Scotland (Witcher *et al*, 2000) which, the authors suggest, means that such anxieties generally disappear, or problems are dealt with, once people start using direct payments. Ridley and Jones found one of the main barriers to implementation was to do with some potential recipients not having had a community care assessment, or that assessments had been 'service-led' rather than needs-led. Lack of knowledge and understanding of direct payments, among service users and staff, was a problem, as were uncertainties about the eligibility criteria, and a fear that local authorities would not allocate enough money to fund the scheme. A concern about people's ability to manage the payments was coupled with lack of information about possible sources of formal and informal support. Some

professionals were worried about the impact of direct payments on their workloads, and also worried that service users exercising choice in this way would reduce the availability of choice for others, but some service users felt increasing choice would drive up the quality of services, as those which were not chosen would not survive.

A subsequent paper by Ridley & Jones (2003) summarised the key findings of their Scottish study as 'a need for person-centred assessment, access to proper support, advice and training, and direct payment schemes that were flexible to allow for different arrangements and for transitions'.

The Commission for Social Care Inspection identified the lack of support services in some local authorities as a factor in the low uptake of direct payments (CSCI, 2005).

Evaluation of direct payment schemes

Maglajlic *et al* (2000) examined the use of direct payments in one London borough among people with mental health problems, learning difficulties, or physical disabilities. Ten service users, 10 staff and 10 carers were interviewed in each of the client groups, and knowledge of direct payments among all groups was limited. Previous poor experiences of services, and a lack of overall information on what was available, had an impact on how some people saw the offer of direct payments, and the need for advocacy and support was identified, including peer support from other people receiving direct payments. Individuals with learning difficulties said they would like to use the payments to fund social and leisure opportunities, and a few wanted to hire a job coach to help them gain employment. Mental health service users wanted information about their rights and entitlements, and training about direct payments, and most wished to use payments for a personal assistant to reduce their social isolation, help with household tasks, and to access mainstream activities and educational opportunities. They all felt they would need help and support to manage the process of employing a PA, and had some anxieties about managing the money. They wanted the evaluation process to be based on user-set standards, rather than those of professionals.

A cross-national qualitative study examined different models of 'cash for care' schemes aimed at older people in five European countries including the UK, focusing on the relationships between employers and employees. It concluded that none of the schemes has a simple outcome or advantage over the others, and each had to be understood in its local context in order to assess its impact on service user empowerment and independence (Ungerson, 2004). The UK's direct payment scheme was reported as empowering service users by enabling them to choose the type of care worker they wanted, and the timing and type of care received. Care workers also reported increased job satisfaction in providing this type of one to one care, although some felt isolated and vulnerable to exploitation when service users asked them to undertake tasks outside their agreed hours or parameters of work.

The *Ticket to Work and Work Incentives Improvement Act of 1999* in America instituted a system designed to provide health care and employment preparation and placement services to individuals with disabilities that will enable those individuals to reduce their dependency on cash benefit programs (Centers for Medicare and Medicaid Services, undated). 'Tickets' were given to service users to be used to

purchase employment services from designated, willing providers, under a system similar to the UK direct payments scheme. However, the National Alliance for Mental Illness found that uptake had been slow, because few providers had signed up to the scheme, and due to social security regulations that prevented some service users from taking part (NAMI, 2003).

Limitations of direct payment schemes

Some authors have discussed drawbacks to the direct payment scheme. Stevens (2001) described the problems that can occur when a service user is unused to being 'the boss' and their personal assistant assumes a more dominant role, and warned that particular sensitivity is needed when one person's workplace is the other's home. He also felt that employment law is weighted in favour of the employee, so that the service user is likely to come out worst if there are major disagreements about how to balance trust with safety issues. Although he concluded that the benefits outweigh the difficulties, he cautioned against underestimating the problems likely to be encountered.

A qualitative study of service users in Queensland, Australia, examined whether the creation of a 'quasi-market' model of service provision had resulted in increased consumer choice for people with a range of disabilities, including mental health problems and learning difficulties (Spall *et al*, 2005). In the 1990s, State funding reforms included the 'promotion of individualised funding arrangements and the cessation of block funding to organisations'. Underpinning this model was the view that competition between providers would enhance the range of choice for service users, and that the promotion of greater efficiency would lead to improved outcomes for clients. The study found that individuals' ability to exercise choice was severely curtailed as in many parts of the state there were either no services at all, or all available services were run by one monopoly provider. Some service users found themselves excluded by strict eligibility criteria, which channelled meagre budgets towards only a small number of people with the most severe difficulties. In terms of service efficiency, some service users reported that costs had gone up while the quality of what was provided had gone down, as agencies were under pressure to increase their throughput of clients.

Although the direct payments scheme has been generally popular with individuals who have accessed it, Perri 6 (2003) pointed out that there have so far been no large scale studies of its impact on service users' well-being. In addition, he argued that some of the problems reported in the Queensland study, such as inadequate funding for individualised budgets and serious limits to service availability, also occur in some parts of the UK.

A ruling by a Scottish employment tribunal about who was legally responsible for the employment of a personal assistant funded through an independent service, was reportedly deterring some social work staff from engaging with the direct payment scheme. The position was clarified by Bewley (2000) from *Values into Action*, who argued that direct payments were not affected by this ruling, and that simple documentation was needed to ensure the rights and responsibilities of the service user's employer were clearly stated.

Direct payments for people with learning difficulties

The position regarding a slow uptake of direct payments by service users with learning difficulties, and the barriers to their access, is similar to that of people with mental health problems, with the additional problem that some local authorities were reported to be struggling with the issues of consent, and management of payments, by this client group (Audit Commission, 2004). One author recommended the Scottish practice of promoting the system be adopted in England (Collins, 2002).

The UK-wide *Values into Action* group's research on direct payments for people with learning difficulties found very few independent support schemes in existence for this client group, and identified the importance of developing high quality, peer support to enable service users to exercise choice and control (Bewley & McCulloch, 2004). The problem of how to provide individualised funding to clients, when most services for people with learning difficulties are purchased through block contracts, was highlighted (Danagher, 2003).

The British Institute of Learning Disabilities' study of what people with learning difficulties found helpful in accessing and using direct payments was one of the first to be undertaken by people who themselves had learning difficulties (reported in Ward, 2003). It also included a national survey of self-advocacy groups. The report's findings are given as different stops along the service user's journey, including the type of support they may need at each.

Another UK-wide qualitative study of the support needed by people with learning difficulties in accessing direct payments was undertaken by a group of people who themselves had learning difficulties, in collaboration with other researchers. They found that parents had a key role to play, generally acting as advocates for the service users' independence, and only presenting obstacles to the scheme when they had insufficient information about it (Williams *et al*, 2003). Although it had been anticipated that there might be a conflict of interest between service users and carers, the study found the main conflict was between whole families and 'an inadequate service system'. Having independent support was also seen as important. In some cases, parents got together informally, or through the creation of formal trusts, to share the responsibilities of managing the direct payments. Holman (2002) also argued for the use of Independent Living Trusts for people with learning difficulties. Similar arrangements can be made to help people with dementia access direct payments through the creation of 'user independent trusts', formed for the purpose of arranging care services for people who lack capacity, and of most use to people with complex, high support needs who might otherwise need institutional care (Leece, 2003). Limitations of the scheme for people with dementia, caused by the recipient needing to consent to receiving direct payments, were identified by Moriarty (2005) who argued that it would be beneficial for an agent, such as a family member or carer to manage payments on behalf of such users.

The Wiltshire and Swindon User Network (WSUN) carried out a Best Value review of direct payments for Wiltshire County Council, demonstrating that people with learning difficulties can take a major role in designing and undertaking such work. They found that changes to social services' internal management and financial processes, and more appropriate support mechanisms, would improve service users'

experience of direct payments (JRF, 2002). They also identified care managers' role in providing information and support as crucial to the uptake and success of direct payments.

In a study in Massachusetts, USA, parents of children with learning difficulties found their equivalent of direct payments valuable tools to exercise choice regarding specific therapies, medications and adaptive aids which they otherwise could not have afforded. These payments also enabled their children to benefit from increased social and recreational activities (Freedman & Boyer, 2000). A survey of children and adolescents with learning difficulties in Florida found service users and their carers were satisfied with a cash payment scheme (Loughlin *et al*, 2004).

A group of individuals with wide-ranging experience as service providers, lecturers, independent consultants, researchers and advocates, some of whom had learning difficulties, identified concerns about the direct payment scheme in the context of *Valuing People* and made radical recommendations for the scheme's future development (Dowson, 2002). Their report argued that the scheme's most important feature was that it created greater separation between the funding and provision of services, putting service users in control, and removing the conflict of interest inherent in the traditional system of care in which, for example, care managers' assessment of individuals' needs are constrained by the availability of resources. Only by bringing such conflicts out into the open, they suggested, can a comprehensive system of individualised funding emerge.

The scope of, and rationale for, the national *In Control* programme was summarised by Duffy (2005a). Designed to 'change the organisation of social care in England so that people who need support can take more control of their own lives and fulfil their roles as citizens', a model of self-directed care for people with learning difficulties is currently being piloted in a small number of local authorities (Duffy *et al*, 2004; Duffy, 2004; Duffy, 2005b; Duffy, 2005c).

Direct payments for people from Black and minority ethnic groups

The Social Care Institute for Excellence summarised the current levels of uptake and the barriers to uptake of direct payments for people with mental health problems, finding particularly low rates among people from Black and minority ethnic groups but offering no explanation for this (SCIE, 2005).

Future developments

Some commentators felt that the current scheme does not go far enough, that a more radical model of individualised funding would more effectively support self-determination for people with learning difficulties (Dowson, 2002), and that personal recovery budgets, to include funding for both health and social care, would be particularly helpful for people with mental health problems (Rankin, 2005a). Experience in Australia suggested that the use of direct payments in a 'quasi-market' can result in less, rather than more, choice for service users (Spall *et al*, 2005).

9.5 Examples of Good Practice

People with mental health problems

The HASCAS evaluation of the national pilot schemes included a number of case studies illustrating effective use of direct payments (Spandler & Vick, 2003). One person employed a PA as a waking night sitter for two nights a week, at times when she felt most vulnerable, which had led to her sleeping better and to reduced incidents of self-harm. As social services could not provide an appropriate worker for a young man with complex needs, a family from south east Asia employed a personal assistant from a similar cultural background to help him increase his social contacts. Another service user employed her mother as a PA to help with social, personal and domestic support, as she was the person most trusted. A group of five clients, with active support from their shared care co-ordinator, pooled their direct payments to fund two artists to run a creative arts group in a geographically isolated area. Although health care is not specifically covered by direct payments, a few people have used accrued back payments to buy time-limited sessions of therapies such as reflexology and counselling.

Reporting further from the HASCAS evaluation, Coldham & Spandler (2005) described two recipients who saved their weekly allocation of PA hours to go out for whole days. Others employed PAs who shared particular interests such as 'walking, swimming, and going to art galleries and museums', which reduced their isolation and social exclusion. Some service users paid for gym membership, taking part in other sporting activities, or undertaking educational courses. Those who took part in physical exercise found this improved their fitness and self-esteem, and helped reduce weight gain caused by medication. Other recipients used payments to attend church-run activities, have driving lessons to travel to where they did voluntary work, to fund respite in a residential facility and to attend a day centre in another catchment area.

A study of direct payments implementation in the north east of England found that the system worked best where there were local 'champions to provide focus and inspiration for the work', and where 'a supportive local authority infrastructure was combined with an understanding of the principles of independent living and a commitment to working in partnership with service users' (JRF, 2004b). A planning tool was developed to help local authorities work collaboratively with service users to develop user-led support services. Practical ways to overcome barriers to implementation were identified, including improving internal communication, reaching service users, promoting and publicising the scheme, and managing issues of pay and recruitment.

Derbyshire Mental Health Services NHS Trust's staff guide to writing care plans has a section on including a Direct Payments Care Plan within the individual's CPA Care Plan (Derbyshire MHST, undated). This includes identifying needs, and identifying how the service will be secured, what support the service user will need and how this will be provided. It also covers the aspects of emergency cover arrangements, monitoring and reviewing the plan, and conditions under which it may be discontinued.

Four flexible finance schemes in Leeds fall outside the direct payments system. Funded by social services, they provide assistance to mental health service users through allocation of cash grants, funding for outreach and drop-in schemes, payments to enable respite breaks for carers and to fund childcare for service users who are parents (Pritlove, 2002). Similarly, a scheme in Lancashire provides vouchers, which enable carers to buy respite care in the residential home of their choice (Burnham, 2001).

People with learning difficulties

Using direct payments to set up an individualised service commissioned by the parents of a young woman with learning difficulties and other health problems was described from the point of view of the organisation providing the services (Rose, 2002). This account included the challenges presented by being accountable to the clients' parents, rather than to statutory commissioners.

Swindon People First, a self-advocacy group for people with learning difficulties, was reported in *Valuing People* as running a direct payment support scheme as well as being involved in research to evaluate the use of direct payments for this client group (DH, 2001c). They also documented their experiences of doing this in a way accessible to people with learning difficulties, which includes examples of how the barriers to accessing direct payments were overcome (Gramlich *et al*, 2002). The Wiltshire and Swindon User Network's successful undertaking of a Best Value review of direct payments (JRF, 2002) was followed by the publication of a guide to user involvement good practice in Best Value Reviews (Evans *et al*, 2002).

Older people, and people from Black and minority ethnic groups

A study of older people's use of direct payments found that recipients reported improved quality of life, motivation and happiness, and in one area older Somali people were able to purchase culturally-relevant services by employing PAs from a similar background, where such staff were not available through social services (JRF, 2004a).

9.6 Methods, Media and Tools

People with mental health problems

A number of publications have been aimed at informing service users and carers about direct payments, as a way of empowering them to exercise choice. These include *'Making choices, taking control'*, aimed at mental health service users, in which information on successful implementation was shared and commonly asked questions were answered (Davidson & Luckhurst, 2002). More recently, The National Centre for Independent Living published a guide to some key issues for users and survivors, which clearly set out eligibility criteria, how to apply, what they can be used for, and what support is available. It also discussed issues of safety, risk, boundaries and confidentiality (Heslop, 2005).

People with learning difficulties

The Department of Health published a large print, easy to read guide to receiving direct payments, aimed at all potential service users, including information on the complex area of employment legislation in relation to care staff whom they might

directly employ (DH, 2004d). This was complemented by the Social Care Institute for Excellence's *Direct Payments: answering frequently asked questions* (Lewis, 2005). The Department of Health also published a guide for local authorities, setting out the information and support which should be provided to help people with learning difficulties access direct payments (DH, 2004c). Easily accessible information on direct payments is also available from the *Valuing People* website at www.valuingpeople.gov.uk

The study by Maglajlic *et al* (2000) recommended that information for people with learning difficulties be straightforward, personalised to the individual, available in a number of formats including tape, picture booklet, symbols and video, with information reinforced by repetition rather than given only once. It also suggested making available a directory of all local available resources, accompanied by a video showing what different activities involved, and 'taster sessions' so that people could try them out without obligation. Mental health service users felt that, as their health and social care needs were often closely linked, they wanted to have joint access to both systems, through more 'visible' access points in familiar settings such as voluntary organisations and user-led projects.

All the publications by the *In Control* programme for people with learning difficulties are written in easily accessible language, using large print and numerous illustrations (Duffy *et al*, 2004; Poll & Duffy, 2005;). Similarly, Mencap's guide to getting help from social services includes a clear explanation of what direct payments are, how to apply, how applications are assessed, and what help and support is available to recipients (Mencap, 2003).

The British Institute of Learning Difficulties has produced a guide on to how to get direct payments, and how to find and employ a personal assistant. This includes an audio CD and sample documentation (BILD, 2003); tips on using appropriate leaflets, tapes CDs and magazines, the importance of self-advocacy groups in publicising the scheme, and the provision of training and support to enable people to take up direct payments.

The Scottish Consortium for Learning Disability publishes a guide to direct payments in Scotland, aimed at people with learning difficulties, their families and anyone who wants basic information on how to get a direct payment. The booklet is available as an audio cassette or CD in English, Urdu, Punjabi and Cantonese. See <http://www.sclld.org.uk/pub/>

10 Focus Groups, Interviews and Email Contacts

10.1 Summary of Key Points

- it was generally agreed that service users have limited choices at present about their mental health care and lifestyle;
- choice can be complex: people need appropriate and sufficient information to enable them to make informed choices;
- advocacy and support workers are needed to support service users in making informed choices;
- there should be wider treatment and medication choices, with more opportunity to discuss options with professionals;
- there needs to be more information on, and availability of, alternative therapies, from both statutory and voluntary sector providers, and self-management programmes should be more widely available;
- service users want to be involved in planning their own care and to have a genuine partnership between them and service providers;
- better information on mental health services and treatment options should be available from GPs and primary care services, to help service users make informed choices at an early stage;
- attitudes of professionals need to change so they no longer marginalise and disempower service users, and service users would like to choose who they see;
- carers feel their views and preferences are not adequately considered;
- Appointment times with GPs and psychiatrists need to be long enough to enable an adequate discussion of the options to take place;
- service users want more information on advance statements;
- service users also want to know more about direct payments in order to decide whether these would be useful for them, and were concerned that they would have adequate help and support if they were to opt for them;
- people from BME groups want to be able to choose culturally appropriate services;
- People in forensic mental health settings feel their ability to make choices is especially limited;
- young service users also feel unable to exercise choice due to a lack of information on the options, and to services' focus on the needs of adult service users;
- there is a need for meaningful involvement between service providers and service users; participants were significantly happier with voluntary sector providers than with the statutory sector, which they felt did not encourage service user choice or promote an adequate range of service options.

10.2 Introduction

The purpose of the mini-consultation was to gauge the views of service users, carers and practitioners on:

- how choice and decisions are made about care;
- the tools that assist users and carers to make meaningful choices;
- the media that are effective in helping users and carers to make informed decisions about their care;
- what methods are available to them, such as advance directives;
- issues of access and engagement, assessment, and care pathways.

10.3 Method

We aimed to identify a number of good practice examples using the NIMHE choice checklist, and other relevant advocacy and voluntary organisations through our literature searches and key contacts. All identified organisations were contacted and attempts were made to arrange focus groups where possible. We also sought to conduct at least one focus group in each of the eight NIMHE regions to ensure a reasonable spread across England and a range of views and experiences.

We developed a topic guide to cover the meaning of choice; what tools, methods and media are needed; and what is already available. The method of data collection was flexible in order to enable people to take part in a way that was most comfortable and appropriate to their individual needs and circumstances. The focus groups lasted roughly two and a half hours, and were recorded through note-taking as well as being tape recorded wherever possible.

10.4 Findings

Eight focus groups were established, five of which comprised service users, one was for carers, and the remainder were for staff members. Individual interviews and email exchanges were also included where focus groups were not possible.

Table 1 shows the areas where focus groups and interviews were carried out in the UK and the type and number of participants who took part. Table 2 provides similar information for those who took part via email.

Table 1. Participants in focus groups and interviews

Region & Location of Service	Organisation through which participants were contacted	Focus groups and individual interviews	Number of participants	Age group
North West: Manchester	Voluntary sector crisis service for mental health service users	Focus group	2 staff	18 - 40
Eastern: Colchester	Voluntary sector drop-in centre	Focus group	5 service users	18 - 68
South East: Sussex	Carers' group	Focus group	5 carers	18 - 68
North East, Yorkshire & Humberside: Scunthorpe & Doncaster	Service user involvement group	Focus group	5 service users	18 - 68
East Midlands: Birmingham	Voluntary sector service user group	Focus group	6 service users	18 - 68
London: Lambeth	BME service	Focus group	11 service users	18 - 68
Eastern: Colchester	Child and adolescent advocacy service	Focus group	4 service users	16 - 20
East Midlands: Nottingham	Service user-run advocacy group for mental health service users	Focus group Individual interviews	3 staff 3 service users	25 - 40 25 - 68
East Midlands: Nottingham	Supported house for mental health service users with a forensic history	Individual interviews	3 service users	18 - 40

Table 2. Email participants

Organisation through which participants were contacted	Number of participants
<i>In Control</i> , voluntary organisation	1 person - Director
BME health forum members of a Primary Care Trust	3 members
<i>Focus on Mental Health</i> , voluntary organisation	1 service user
GP	1 GP/carers

10.5 The Nature of Choice and Empowerment

Many service users and carers were unclear about the meaning of choice, especially its significance to them. Many participants viewed choice as complex and felt they needed more information about what choices were available to them. Overall, service users were very sceptical about what choices they had.

'My view is that choice empowers people and it gives them a say in their treatment from the initial diagnosis right through to treatment and then on to recovery and their future and choice in what sort of care they receive; how they want to be treated basically. It's an ongoing thing but don't feel that there are enough choices at the moment, not at all.' (Service user)

This service user's view was that the right kind of information empowers them. Almost all the service users and carers commented that there was not enough information available to be able even to think about choice.

The service users and carers were happy to hear that there are good initiatives to address their needs, but they were concerned that these were very patchy and the only good practice they were aware of comes from voluntary organisations. They would like a centralised source of information, backed up by advocacy services. Confidence and self-esteem are often reduced when people have mental health problems, and service users would welcome projects that can promote their recovery and build on self-confidence. One example of a good initiative is a service user-run advocacy service for people with mental health problems and learning difficulties, where the focus is on simple choices to help with their recovery.

'Here we give real choice; we are guided by the service users and we do whatever they want to do. Here we give choice without restriction. For example, when they wanted a health and nutrition mental health forum we set it up. We do simple things like give them advice on how to get the best care.' (Staff)

The staff in this service reiterated that people with mental health problems have limited choices at present. They emphasised that they need to be given proper information and advice to make informed choices, but also help with accessing and interpreting information. They felt there was still a long way to go.

'They need to make things a lot more user friendly. Information can be interpreted differently; therefore having an advocacy worker is an important and good idea. It is all about interpretation.' (Staff)

These staff said it was also about making simple life choices and then getting on with life, and empowering the service user to cope with their problems and do more.

'A service user wanted to do some art therapy and what started as a small event now developed into a therapeutic value. Now he is giving art therapy for other users.' (Staff)

Promoting and supporting life choices is a very important aspect of getting the issue of mental health choice across.

10.6 Treatment Choices

All the service users participating in the focus groups wanted more treatment choices. Most of them wanted to have alternative treatments such as counselling and one to one talking therapies. All were in favour of therapies like reflexology and massage, which they were receiving from voluntary organisations like Mind, but they wanted to be able to have these treatments from statutory services.

Most felt that statutory services give far too much importance to a medical model rather than looking at the problem holistically.

'Choice to me is actually being offered some alternative therapies in that waiting period in time to see a psychiatrist, because alternative therapies have been my life saver not necessarily drugs. I am not saying drugs are not the answer for some people and I may have needed them some of the time, but alternative therapies are getting me my life back.' (Service user)

'I think that you go to a GP sometimes the only choice is to get well yourself or end up in the mental health system and the choices like, when you say I am feeling a bit down, I am feeling tearful, talking to people is not enough, what is the next thing? Some choices rather than just tablets and choices like getting a prescription to go down the gym and being able to exercise to see whether that actually makes you any better or not, that kind of choices and I don't hear many people say that they have been offered that. I certainly didn't experience that when I went to the GP who said those kinds of things, those alternatives were not offered.' (Service user)

'There are a lot of talks about now that your diet might have a big influence on your mental health but nobody has ever asked me my diet, they have asked whether I am overeating or under eating, but no one sort of said what are you eating so even to see a dietician would be useful and yes, perhaps have a councillor whom I could discuss things with or group therapy, other specialist.' (Service user)

10.7 Medication Choices

Most of the participants thought medication alone did not help them solve their problems, and they seemed to dislike their side effects. They also wanted choice in the type of medication they were offered. Many of service users were not in favour of the traditional medical model where the only option available to them was medication. There was general agreement about a lack of information given by professionals regarding the nature of medication and the potential side effects. Service users and carers were concerned about not being able to get access to the newer, atypical medications.

'Choice in medication is an important issue. My friend wanted to have new medication; they did not give him any due to funding difficulties. Government should make more money available to get the best medicine without cutting corners.' (Service user)

Many of the people who took part in the focus groups said that they should be allowed to choose whether to take and remain on medication or not, especially when they were well. Maintenance medication was a key issue.

'As for taking medication when you feel well, I came off my maintenance dose and managed for quite a few years, when people are feeling well, they should be allowed to have the choice whether they take a maintenance dose or whether they manage without.' (Service user)

Service users were concerned about the lack of information given to them by the professionals about their medication and their side effects and the availability of other medicines.

'First time when I was ill my illness wasn't explained to me, the medication wasn't explained to me so when I came out of hospital, I was tired all the time with the medication and I stopped taking it, and nobody told me that I would relapse. Also when I asked the psychiatrist what were the side effects of the medication he said there are no side effects. Well, when you read the side effects, there were all sort of things and I presume the only reason he told me that was so I didn't stop taking it. But people should have the choices when they first become ill because when you are ill, you are not at your most assertive and you are extremely vulnerable so you should be told what your illness is about and also about the medication, then you can make informed choice.' (Service user)

10.8 Self-Management Programmes

The service users wanted more self-management programmes that would help them to take control of their mental health problems. Many service users believed that there were not enough self-help programmes like this. The voluntary organisations Mind and Rethink run self-management programmes for service users, but service users would like such programmes incorporated within the NHS.

'Once I was feeling better there were things like anxiety management, stress management, panic attack management and I took advantage of all of them. Some did work and some did not and I still use them now. So that was a choice there. I was offered the choices partly through voluntary organisation and partly by the occupational therapists on the outpatients department.' (Service user)

10.9 Choice in Care Planning

For some people with mental health problems, care planning and an individual care plan is already in place. However, the majority of the service users seemed to have had negative experiences of the Care Programme Approach. They were concerned that the written care plan was not being followed through, and there was a lack of

action, with still a long way to go to bring individualised care planning and delivery into everyday practice. Service users said they wanted to be told about care planning under the Care Programme Approach.

'It was 3 years before I knew I had a care plan and the only reason I knew that it existed is because I came to this group (MIND).' (Service user).

People do want to know what is available for them. There was general agreement between the service users and carers that they do not know much about choice in care planning.

10.10 Choice in Service Planning and Delivery

The gap between what services do and what people find effective for better mental health has been identified by Rankin (2005). The service users from our focus groups reiterated this. They were very happy with voluntary organisations and the services they offered, but were not satisfied with the statutory services. There was a general agreement that the NHS should acknowledge voluntary organisations' services and give them funding for good initiatives.

10.11 Primary Care

Many of the service users and carers reported that their GPs' practices were not well set up for looking after people with mental health problems. They thought that since GPs were their first point of access, they should provide them with proper information and direct them to the appropriate services. They felt doctors did not spend enough time with them and their training in caring for people with mental health problems was inadequate. Service users said that if the GPs could detect their symptoms early on, and monitor their progress, then crisis situations could be avoided. Many of the users said that they were taken seriously only when they reached a crisis point, but prevention and early identification would be a better option. They would be happy simply to have someone listen to them.

Most of the service users wanted a simple, clear information pack from their primary care service, including:

- an explanation about the illness;
- what local voluntary organisations can help with;
- medication on offer and an explanation of its side effects; and
- any alternative therapies on offer and where they can access them.

Many service users stressed wanting this information at the onset of their illness, instead of being referred to a psychiatrist with a wait of more than six months.

'Well, if you go to the GP, you are diagnosed with a mental illness, you should be given the information about that mental illness then, not wait until you go into the system or see a psychiatrist. You should be given it straight away.' (Service user)

Another service user commented:

'My opinion is if services could be offered to people before they get into that psychiatrist route they won't be pressured.' (Service user)

10.12 Choice of Professionals, and Professionals' Attitudes

Service users and carers would like a choice of GP, psychiatrist, CPN and key worker but would want to see the same person each time. They felt that if they had a good relationship with the professionals their recovery would be enhanced, but they were concerned about the attitude of the professionals.

'I think a bit more humanity from the staff is needed as well, because if you are a professional, you are expected to know what is possible so I think that actually working with the person is essential. If they haven't got humanity, you haven't got a choice.' (Service user)

10.13 Carers

Carers were frustrated and disillusioned with the care their loved ones are given. They felt that professionals did not listen to them and gave little information. They felt that they were not regarded as part of the service users' care; rather they were treated like part of the problem. Their main support came from voluntary organisations.

'I actually went to my partners' meeting with the psychiatrist but I didn't feel I could do anything. I was just there to support. I felt I am not part of it.' (Carer)

'Carers are very under valued.' (Carer)

Carers were also concerned about lack of support they got. Many commented that their health was also suffering, due to the stress, and there was no one to help them.

10.14 Time Spent with Professionals

Nearly all the participants complained about the lack of time spent with the professionals, whether it was psychiatrist, GP, or other professional involved in their care. They also wanted to be able to choose their health care professionals. They wanted professionals to treat them with respect and 'listen' to them. Professionals' lack of understanding and listening were highlighted throughout all the focus groups.

'One thing I would like to see is when someone who is ill, the first meeting with the psychiatrist, they are given enough time to go through everything, because I had the experience where I was in the room for 5 minutes and he wrote across the page 'financial difficulties' and I said 'Whoa. You don't even know me'. But I did make my own choice then, I went and got him changed and after that, I seem to have got a lot better service after being changed to somebody else. It is probably because I am stronger person and on that particular day, I was a bit assertive.' (Service user)

Another service user commented:

'When are they going to realise that a psychiatrist needs to be allocated more than 10 minutes per client, because what choices can you have when you are there for only 10 minutes.' (Service user)

'One simple word, 'LISTEN! Listen to the people who use the services and that is where you are going to get your information from.' (Service user)

10.15 Advance Statements and Advance Directives

Recent government initiatives on advance statements were welcomed by all the participants. However, service users would like more information on such initiatives to enable them to make an informed choice. The main concern seemed to be the lack of information on advance statements to enable them to make a proper choice. A Mind user involvement group had been involved in working with its local PCT to bring out a patient charter in which its members had designed an advance directive statement form. This good practice example was being promoted by the PCT with the involvement of the service users. The majority of the service users thought advance directives were a good method which would allow them to have a say in their treatment.

10.16 Direct Payments

People had mixed views on direct payments and many had not heard of them. They wanted more information. Some said that the scheme would be good if it worked, but they were sceptical about this. People needed more support to make such choices. They were concerned about simple details such as budgeting and shopping skills, and found the idea of direct payments daunting. People were already worried about not receiving their benefits, and felt that having direct payments might complicate matters.

Some of the staff thought the scheme might work for some service users but not for all. They also wanted to see the system properly set up.

'I am sure for some people it is a great idea, but not all the people are capable of making such decision.' (Staff)

Carers were very sceptical about direct payments, and they wanted to know whether this new initiative would be sustainable.

Some of the positive comments from the Director of the *In Control* programme were obtained via email.

'My views on direct payments are very positive - but must be seen in a broader context - there are at least 6 different ways in which someone can control their own funding - DP route is just one - this whole area needs much more clarity. It is particularly important that for people with mental health problems the mental health advantages that can come from individualization are not lost by not

exploring ways in which others might be useful in controlling funding by using Indirect payments, Trust Funds, intermediate Agencies, individual Service Funds or effective care management.’ (Director, In Control)

10.17 People from Black and Minority Ethnic (BME) Groups

People from Black and minority ethnic groups with mental health problems thought that few appropriate mental health services were available to them. Many of the service users needed to know where to get proper choice and culturally appropriate services, and said that this should start with GPs. Many of them had negative experiences of GPs, and felt that professionals should be educated to be culturally aware of their particular needs. They would also like some education for themselves so that they could be better informed about the choices available to them.

‘I think that the doctors need to be educated that there are other alternatives and if the patient comes in and says ‘I’m depressed’, It shouldn’t just be that the doctor says ‘ OK, take these tablets, go away then come back 2/3 weeks later to see what effect it has had on you’. So that is where it should start, they should be able to spend more time with us and look at the whole person.’ (Service user)

BME service users wanted more services like ‘Cares of Life’ that would understand their needs. They also thought there was a cultural dimension to understanding their mental illness. The service users were sometimes isolated from their family because the family did not seem to understand they were ill and needed help.

‘Your family are the first to leave you alone when there is something wrong with you. They don’t understand your depression, your trauma; they don’t understand your pain so you stop talking. The pain is not physical, it is mental and they cannot understand it and you keep talking because you are frustrated and they do not understand you. So you just stop talking and then you deny that you are in trouble - those are my experiences.’ (Service user)

The service users also wanted professionals to understand and take into consideration their spiritual beliefs.

‘Mental health is a psychological thing but it is also spiritual thing as well and a lot of them cannot understand that black people are very spiritual people and they can’t seem to get to grips with anything - as soon as you mention certain things, they just strain to understand you.’ (Service user)

10.18 People in Forensic Settings

People with mental illness with a forensic history felt they had very little choice available. Those living in supported housing felt that, because of their forensic history, choices were especially limited since public protection was seen as paramount. They blamed the media for the lack of understanding about their situation.

'Media needs to be educated to understand mental illness and the debilitating effects it has on us the sufferers.' (Service user)

'The public need to be educated to differentiate the illness from the person and not label me as a nutter.' (Service user)

They wanted more choices regarding treatment and medication. The supported housing scheme in Nottingham was a good example of how choice and support could help people with mental health problems and a forensic history. The service users there were involved in preparing their care plan and were receiving better care. The residents said they would like more services like this. The staff were providing support to make the transition from hospital and a secure setting to more independent accommodation in the community, which ultimately they wanted.

10.19 Young Service Users

Young service users were not aware of the choices around for them. They felt they needed more information so they could make better choices.

'I don't think that anyone is clear what is out there, including the services themselves.' (Young service user)

'A lot of organisations don't have the necessary information and they don't know where to look or who to go to, other than their doctor. But even the doctors cannot refer you to a lot of the places anyway, or they don't know what is good for you.' (Young service user)

'It seems that the only options given to you are either medication, counselling and at the end, being sectioned; that is it, that is all you are offered. Sometimes you don't even have the choice. That is all that is open to you.' (Young service user)

Confidentiality was one of the main issues raised:

'I think that you should have the right to confidentiality because the school will not listen when you say that you don't want people told, they will tell anyone because that is just what they feel like doing and that is irritating. That should be stopped. You do start to have confidentiality in your school after a while, but only after you have shouted at them a lot; it is not a thing that they do without this.' (Young service user)

Young people with mental health problems wanted treatment options similar to those available to adults, such as alternative therapies and counselling. But they wanted services to be separate from those for adults and for counselling to be tailored to their specific needs.

'I think that they want choices of what they can do, like if you went to a service, the choices that they can offer you...such as counselling, they do one thing, they don't give a choice of how you want to do it. They do it by the book in a way - by

the textbook - and sometimes that doesn't work. I know from experience it doesn't work with a lot of young people, because in some areas they use adult techniques when the person is a young person so this is not going to work. I think that they should give them more choice. They should say how do you want to go about this? What do you want to do...draw, write, make music, and go out somewhere, whatever? Some services do that but not a lot of them. I have experienced counselling services and got on with it, this was a statutory service. I was referred there by a doctor and had never heard of it before then. They should ask you how you want to things and what you want to do, not just set out how things are going to be done so either you do it this way or you don't or it doesn't work.' (Young service user)

Young people would like their services to be more flexible, and not to have time constraints, especially not being restricted to school hours.

'Times should be more flexible. Like this place here, it is open most days 9 - 5, what if at 2am you want to kill yourself? What are you going to do then? Because no one is here, or that you are at school. Times should be more flexible. You can't just say that we can't do it because we can't be bothered because we need to go to bed. There needs to be something there all the time that you can rely on.' (Young service user)

The focus group participants re-emphasised the lack of information available to them. They were under the impression that GPs and schools do not know enough about their problems and how to care for them. They would like training for the professionals who were involved in looking after them.

Young people are very much against compulsory admission to hospital under the Mental Health Act (sectioning). They felt that because of fear of being sectioned, they clam up and do not reach out for real help when they have problem.

'You don't want to talk to someone because you think that if you open your mouth, they will put me in that horrible place and I might not get out again.' (Young service user)

'The weird thing with young people, they know the mental health units, they know what they are and where they are but it stops there. And once they hear that young people with mental health illnesses get locked up there, that's it, they clam up, they don't want to know.' (Young service user)

Young people said communication was essential between different services, including those in the voluntary sector. They would like the services to communicate between different departments as well, as services need to communicate better with young people.

'The biggest one is network. The organisations should be talking with each other and I think that this is where it can start and that is where it should start - and not be competitive.' (Young service user)

'It is basically just communication. I think that if they all started communicating, then things would gel, it would run a lot smoother, just because they are communicating.' (Young service user)

Young people thought GPs and other professionals did not spend enough time with them to get the help they needed. Ten minute consultations were insufficient.

'... I think that they don't have enough time to actually talk to young people properly. They have so many people in the community and you have to book 3 weeks in advance to see them. I don't think that their training is updated that much on things.' (Young service user)

'... you have 10 minutes to tell the doctor what I am going through, how I am feeling and for them to do something about it. They type it into the computer and that is that.' (Young service user)

The young people were concerned about the transition period from mental health services for young people to adult services. This seemed to be a major issue for them, and they felt the age limit for going into adult services was not viable.

'They will get rid of you at 16 and try to put you on to adult services and that is your only choice.' (Young service user)

'The problem with that is that young person services will get rid of you at 16 and yet adult services will not take you until you are 18. There is no transition between the services at all.' (Young service user)

'So you have this large gap in the middle where you can't do anything. In that time though, say you are getting better and they say that you have to go now, you just go straight down because you haven't got that support and it gets to the point where you don't want to go back in; what's the point because they are just going to abandon you again.' (Young service user)

They wanted all types of media to be used to get information about mental health across and favoured radio, music and television. They also wanted mentoring by other service users who had gone through similar difficulties and could guide them and help to get appropriate support. They felt that as they represent the country's future, their needs should be met in a special way.

'The young people are the future and the government should be looking to help young people and give them something to go to, so that they are there for the future.' (Young service user)

10.20 Contributions via Email

In Control - services for people with learning difficulties

In Control, which works primarily with people with learning difficulties, saw choice as about who provides help or advice, and what direction an individual's life should take. The most important aspect of mental health choice is respecting the need of

the individual to live a life that makes sense and supports the best possible community engagement. One of the important aspects is to provide services in a way that is person-centred. *In Control* uses a process called supported decision-making, providing information and support, to make an agreement, which may also be useful in the mental health field. They have published a planning tool 'In the Driving Seat', and guidance on choices, 'Top Tips and Keys to Citizenship'.

People from Black and minority ethnic groups

People from BME groups would like information to be provided in simple English as well as other community languages, which can be easily understood. Ethnic TV channels could be used to raise the profile of the issues. It is also good to employ people from the BME community to do mental health promotion and prevention work, especially as it seems that very often people from BME communities are not referred until they have reached a crisis stage.

10.21 Examples of Good Practice

Focus group discussions identified some of the good practices available for service users. In Doncaster, a voluntary organisation has a well-established user involvement group which works with the statutory services. Their user involvement group has successfully set up a 'hospital to home group' whose overall aim is to give inpatients the opportunity to join a group facilitated by people who themselves have experience of using mental health services, some of them as inpatients. This provides inpatients with information about useful services available in the community, and offers them an alternative to groups facilitated by paid staff.

A 'Facilitated and Supported Discharge Team' for older people with complex physical, psychological and social needs was piloted by County Durham and Darlington Priority Services NHS Trust. Interventions were provided for maintenance of the individuals' health, well-being and independence, and for the support of carers and third parties. For example, on discharge, staff took the person home, made sure they had food and that the gas and electricity were on, then visited every day for a week to check that everything was going well. Sadly, despite a positive evaluation in terms of service users' and carers' satisfaction, reduced hospital readmission rates, and prevention of admission to residential homes, PCT funding for this team was not continued.

10.22 Methods, Media and Tools

Most of the service users and carers are in favour of using all media to support them. They would like information packs, leaflets, the Internet and TV to be used; the latter to promote mental health information and prevention. It would also be especially good for people with literacy problems. They would be happy if service users could be used in a positive manner to talk about their life experiences, which would reduce the stigma of mental illness. They felt there should be more programmes on TV from celebrities talking about their illness and how they recovered.

11 An International Perspective on Choice in Mental Health

11.1 Summary of Key Points

In a selective overview of four countries' national strategies and policies on mental health, we found a number of common themes:

- the language of choice is not universally used, and it is hard to locate any free-standing documents looking specifically at patient choice in mental health. However, often choice issues are implicit in publications that refer to patient empowerment, involvement and participation. More recent documentation uses the language of choice more frequently, as it gains hold as a central principle for developing services;
- choice is seen as a vital ingredient in the recovery model of mental health care, without which people's recovery and integration in society is significantly hindered, and people cannot regain control of their lives;
- good information is crucial if choices are to be meaningful, along with support for people to help them make often complex choices. With the help of professionals and advocates, people with mental health needs should be able to access good quality information not only about their health care but about all aspects of their lives, such as housing and employment;
- there is broad agreement from governments, service providers, service users (generally referred to as consumers) and carers that service users should have more, and better informed, choice. However in practice choice is not commonly available. This may arise from health professionals' reluctance to offer choices, or though limitations on available services, primarily as a result of financial constraints. Having a choice is meaningless if there is not a range of affordable, culturally sensitive and appropriate services from which people can choose.

11.2 Introduction

This section gives a selective overview of how national mental health organisations in four countries regard choice within their overall mental health strategic and policy framework.

The countries we looked at were Australia, New Zealand, the United States (with a particular focus on New York) and Canada. An overview of these countries' national policies was supplemented by individual personal perspectives. These were kindly provided by Steve Morris of the Mental Health Council of Australia, Judi Clements of the Mental Health Foundation of New Zealand, John Allen of the Office of Mental Health, New York and Penny Marrett of the Canadian Mental Health Association.

The documents referred to in this section may be found via the websites cited for each organisation. (Specific referenced examples of literature about choice and

good practice from these countries may be found in the earlier Literature Review sections of this review.)

11.3 Australia

In Australia, at a strategic planning level, the language of choice in mental health appears to be rarely used. Rather, national (federal) mental health strategies tend to refer to 'consumer and carer participation'. For example, the government's 2003 *National Mental Health Plan 2003-2008* (www.dh.sa.gov.au/mental-health-unit/documents/mhplan.pdf) does not actually contain the word 'choice'. However, there are exceptions, such as the Australian Foundation for Mental Health Research (www.affirm.org.au), which talks about creating a more supportive environment of increased choice and access to effective treatment and prevention options.

The discussion of consumer and carer participation runs through the national mental health strategy as well as documents produced by commentators on that strategy. Broadly, the national Plan acknowledges that while formal mechanisms for consumer and carer participation have been put in place, these do not comprise the meaningful participation that is required. It accepts that participation across the spectrum of care from promotion and prevention to recovery has not yet been achieved.

The Plan's stated aim is to strengthen mechanisms to facilitate the genuine participation of consumers, families and carers in decision-making at all levels, including individual care and recovery plans. While not explicit, this suggests that increasing consumer choice is an integral part of the government's agenda.

The lack of an effective consumer and carer participation is picked up strongly by the Mental Health Council of Australia (www.mhca.org.au). The Council was established in 1997 to bring together consumers, carers, non-government, government and private service providers to provide advice to governments and to monitor and analyse national mental health policy, resource allocation and outcomes.

In its report *Out of Hospital, Out of Mind: A Report Detailing Mental Health Services in Australia in 2002 and Community Priorities for National Mental Health Policy for 2003-2008* (April 2003) the Council acknowledges that the principles of consumer and carer participation appear to be enshrined in National Mental Health Policy and Plans. However, it argues that genuine consumer and carer involvement is lacking at all levels, and that there has been insufficient movement in mental health towards universal principles of health care such as choice and participation, which remained token.

Carers are quoted in the report as saying 'Carers are never included in the treatment plans. They're just not consulted' and 'Carers feel totally disempowered ... There's a complete lack of negotiation'. A consumer states 'The [doctors] just tell you ... what you want and what you need!'. Consumers commonly reported mental health care as being something that 'is being done to them' as opposed to being developed and delivered in partnership with them. Many consumers reported strong feelings of disempowerment, frustration and neglect by the system.

The message is repeated more recently in the Council's *Submission to the Senate Select Committee on Mental Health's Inquiry into Mental Health 2005* (May 2005). The submission suggests the national strategy has established consumer and carer participation in service planning and delivery as a desirable goal, though there is little evidence it has progressed into a practical reality. It calls for a change in service culture and practice by the mental health workforce so that they recognise the rights of consumers and carers. It adds that funding problems have resulted in restrictions on the range of services, especially in the community, available to consumers. Only lip service is paid to consumer and carer participation in the planning and management of resources.

The National Consumer and Carer Forum's 2004 *Consumer and Carer Participation Policy: A Framework for the Mental Health Sector* (www.mhca.org.au/Publications/documents/ConsumerandCarerParticipationPolicy.pdf) is a guide for all organisations involved with mental health to use in the development and implementation of consumer and carer participation policies. Its definition of consumer and carer participation is '*either voluntary or paid participation by consumers and carers in all aspects of mental health care*'. While this does cover individual treatment, recovery and relapse prevention plans (so, indirectly, invoking patient choice) the document is very much targeted at consumer and carer representatives and the advisory role they play at the individual, local, regional, state, and national level.

In sum, national policies in Australia tend not to address the question of choice directly. Although consumer and carer participation is built into national strategies, the reality - accepted by the government - is that it is often lacking in local services through either a lack of will or service shortages.

A perspective from Australia - Steve Morris

Steve Morris, Senior Policy Officer at the Mental Health Council of Australia, confirms that in Australia the language of 'choice' is presented as consumer and carer 'participation'. As such, it is important to make the distinction between 'participation' of consumers (and their carers) working with their clinicians to develop their individual treatment plans, and 'participation' in an advisory capacity (which is not really to do with choice). At the individual treatment level, an empowered and informed consumer needs to be matched by a clinician with the right attitude and resources. Equally importantly, the presence and affordability of particular types of services, as well as the ability of the consumer to access these in a timely manner, will impact on the amount of choice available to consumers and carers.

In his view, key issues in implementing choice in mental health for Australians include:

- availability of a range of services to support consumers and carers. These may be health services from a psychiatrist, GP, Occupational Therapist and/or psychologist, or social services such as housing or employment assistance, and may be required variously in community and acute care settings. In Australia, people living in remote and rural areas in particular are limited by what services are available locally. For other Australians living in urban areas, geographical boundaries for particular services limit their availability.

- access to appropriate mental health services in a timely fashion. Even when services are actually present in their area, consumers and carers all too frequently report they are unable to access them in a timely manner. This is particularly the case for promotion, prevention and early intervention services, meaning many people end up in crisis before they are able to access help.
- affordability and the ability of consumers and carers to choose the mental health services they want. Funding structures in Australia favour care provided by public psychiatrists and GPs, leading to a reliance on medication as the sole treatment option available to clinicians. Access to allied health professionals such as psychologists is restricted by the financial resources of consumers and their family. The introduction of the *Better Outcomes in Mental Health Care* initiative (www.adgp.com.au/site/index.cfm?display=2550) and *Chronic Disease Management Medicare Items* (www.health.gov.au/internet/wcms/publishing.nsf/Content/pcd-programs-epc-chronicdisease) go a small way to improving this access by providing funding for referral to allied health professionals, but both options are limited by rules and caps and require such large co-payments that they are beyond the economic means of many consumers.
- information about choice is essential so that consumers, carers and clinicians are aware of what services, resources and options are available to them in their area.

People can be best supported to make choices through education and empowerment. Providing knowledge of the causes and impact of mental illness, treatment options, of how the various parts of the mental health system function and relate, and of individuals' rights and responsibilities is the first step to empowering consumers and carers. The *Clinical Practice Guidelines* (www.ranzcp.org/publicarea/cpg.asp#consumer) developed by the Royal Australian and New Zealand College of Psychiatrists (RANZCP) are an excellent example of empowering the community through education.

Lastly, Steve Morris believes that strategies aimed at educating the 'supply' side of mental health care – mental health workers, administrators, policy-makers – are also necessary to ensure acceptance and understanding of consumer and carer needs. Two such strategies in Australia are represented by the *National Practice Standards for the Mental Health Workforce* ([www.health.gov.au/internet/wcms/Publishing.nsf/Content/mental-pubs/\\$FILE/natpracstand.pdf](http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/mental-pubs/$FILE/natpracstand.pdf)) and the *National Standards for Mental Health Services* ([www.health.gov.au/internet/wcms/Publishing.nsf/Content/mental-pubs/\\$FILE/natstand.pdf](http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/mental-pubs/$FILE/natstand.pdf)).

11.4 New Zealand

The New Zealand Ministry of Health (www.moh.govt.nz/mentalhealth) set strategic directions for New Zealand's mental health services in 1994 (*Looking Forward - Strategic Directions for the Mental Health Services*, June 1994). This strategy document provided goals, underlying principles and national objectives to make sure the needs of those who use mental health services are met.

The word 'choice' does not appear in this document (perhaps an indication that it was written over a decade ago when providing or extending choice was not a primary policy aim) although, among problems cited, it does refer to a lack of provider responsiveness to the needs of consumers, caregivers and their families, and people's 'preferences' are mentioned. The 14 principles underpinning the strategy include:

- encouraging services that empower individual consumers and their families/whanau and caregivers (Maori are the indigenous people of New Zealand, and 'whanau' is a Maori word broadly meaning 'extended family')
- ensuring Maori involvement in the planning of mental health services for Maori and in designing services appropriate to Maori needs
- increasing the sensitivity of services and support systems to the changing needs and preferences of people.

The strategy was followed up in 1997 by a further document aiming to accelerate action (*Moving Forward: The National Mental Health Plan for More and Better Services*, September 1997). This repeated the original strategy's principles, but added three more, the first of which was:

- encouraging programmes and services that enable individuals, families and communities to increase control over, and improve, their mental health and wellbeing.

There is a particular focus in the 1997 plan on services for Maori. It sets out a national objective: to continue to increase responsiveness to the special needs of Maori, by providing access to both kaupapa Maori and mainstream services. The plan acknowledged that not all regions provided services at a level that gave Maori an adequate choice between mainstream or kaupapa Maori community mental health services. ('Kaupapa' is a Maori word meaning 'philosophy'. In this context, 'kaupapa Maori services' means those which are culturally appropriate.) It called for significantly increased purchasing of community mental health services from Maori providers, and set a target that by July 2005, 50% of Maori adults would have a choice of a mainstream or a kaupapa Maori community support mental health service.

More recently, in June 2005, the Ministry of Health launched *Te Tāhuhu: Improving Mental Health 2005-2015: The second New Zealand Mental Health and Addiction Plan*. This outlines the government's policy and priorities for mental health and

addiction for the 10 years between 2005 and 2015, and provides an overall direction for investment in mental health and addiction.

The Plan sets out a number of Outcome Statements, including that all New Zealanders make informed decisions to promote their mental health and wellbeing, and that people with experience of mental illness and addiction receive recovery-focused mental health services that provide choice and promote independence. Among the challenges set are to build and broaden the range and choice of services and supports for people who are severely affected by mental illness and to broaden the range, quality and choice of mental health and addiction services for Maori. The Plan again places a particular emphasis on the needs of Maori, and calls on services to promote choice by supporting the implementation of kaupapa Maori models of practice. At the time of writing, the implementation of the Plan is at pre-consultation stage awaiting Cabinet approval.

The Ministry of Health has also recently published a *National Mental Health Information Strategy* (June 2005). Consumers, carers and family are, because of their number, cited as the principle stakeholders, as they have the largest requirement for easy access to information that will help them make informed choices. The Strategy points out that consumers and informal caregivers want improved access to general information about different mental health conditions and their associated treatments, and access to a directory of mental health service providers.

The New Zealand Mental Health Commission (www.mhc.govt.nz) began work as a ministerial committee in September 1996. A key part of its role is to ensure the implementation of the national mental health strategy by monitoring and reporting on the performance of key agencies. In its *Blueprint for Mental Health Services in New Zealand - How Things Need to Be* (December 1998), the Commission argued that historically, mental health services have failed to use a recovery approach. Recovery could never take place in an environment where power was used to coerce people and deny them choices. It linked choice with responsibility. Responsibility was essential to facilitate recovery. People with mental illness who took responsibility for their lives could more easily learn from their mistakes, build on their successes, and make positive choices.

The Blueprint called for mental health services to offer the greatest possible independence and choice to service users and to involve service users as equals in all decisions made within the services that affect users' lives. It also sought to ensure that people with mental illness have equitable choice in all publicly funded health services. It proposed that the range of housing and daily living options should include specific choices for Maori, including kaupapa Maori services and services to meet the needs of those with concurrent alcohol and drug problems. Maori should be entitled to choice of access to both the full range of mainstream services and to kaupapa Maori services. They should also have the choice to converse in their own language and access to the full range of choice of Maori healing methodologies, processes, and natural medicines, as well as clinical treatments including access to new medications, and recovery approaches.

A number of more recent Commission publications include issues around choice. For example the Commission's Annual Report for 2005 refers to how to ensure participants have informed choices and appropriate supports when undertaking anti-discrimination campaign work. And a paper looking to the future (*Our Lives in 2014: A recovery vision from people with experience of mental illness for the second mental health plan and the development of the health and social sectors*, June 2004) envisages services giving priority to offering service users - including people subject to compulsion - an optimal range of choices, with people using Maori services having choice and control over their own recovery and leadership in the services they use.

The Mental Health Foundation of New Zealand (www.mentalhealth.org.nz) is an independent organisation whose vision is, nationally, to lead mental health promotion ('the process of enabling people to gain control over and improve their mental health and wellbeing') and whose mission is to improve the mental health of all people and communities in New Zealand.

The Foundation focuses strongly on the importance of providing information to enable people to make choices:

'People who have information can make informed choices. It is up to each person to decide what mental health is and what it means for them. We believe that providing accurate and helpful information is vital to the process of enabling people to gain control over and enhance their mental health and wellbeing. This includes considering factors that determine our mental health status such as age, gender, ethnicity, income, education, housing, sense of control over life circumstances and access to health'.

The Foundation's website is designed to provide access to quality information and resources.

Interestingly, the Foundation's own literature review on mental health promotion (*A Review of mental health promotion literature and analysis of evidence to inform mental health promotion practice in Aotearoa/New Zealand*, August 2003) does not refer to choice, although it lists a Ministry of Health paper that defines mental health promotion as 'the process of enhancing the capacity of individuals and communities to take control over their lives and improve their mental health'. The Review focuses primarily on the 'self determination' of individuals and groups, enabled by access to cultural, economic and social resources.

A perspective from New Zealand - Judi Clements

Judi Clements, Chief Executive of the Mental Health Foundation of New Zealand, believes that the involvement of service users/consumers is an essential prerequisite to establishing the concept of choice and creating the necessary range of available choices. As she puts it, 'a service user in the UK once said to me "I want a life. Not just a service"'.

She considers that the key issues around choice can be summarised as:

- accessible information for consumers, carers and professionals;
- honesty about options;

- willingness to take risks and be creative (on the part of the provider in particular);
- mutual respect between consumers and professionals and the creation of equality in exchange;
- the availability of advocacy for consumers - needed sometimes to level the playing field;
- cultural competence on the provider side.

To ensure people are able to make choices about their care, she believes it is vital for consumers to be able to access a good range of information, including aural and visual, and the ready availability of translation and interpreting. Advance directives and service user designed crisis cards also have a central role to play.

11.5 United States of America

President Bush established the President's New Freedom Commission on Mental Health in April 2002, to identify policies that could be implemented by Federal, State and local governments to maximize the utility of existing resources and improve coordination of treatments and services. The Commission reported in July 2003 (*New Freedom Commission on Mental Health, Achieving the promise: Transforming Mental Health Care in America*, Item Number SMA 03-3832, available from www.mentalhealthcommission.gov/reports)

The Report argued that successfully transforming the mental health service delivery system relied on services and treatments being consumer and family centred, geared to giving consumers real and meaningful choices about treatment options and providers, and not being led by the requirements of bureaucracies. However the complex mental health system overwhelmed many consumers. They often felt bewildered, given they had to access mental health care, support services and disability benefits across multiple, disconnected programs that spanned Federal, State, and local agencies as well as the private sector.

Nearly every consumer of mental health services who submitted comments to the Commission expressed the need to participate fully in his or her plan for recovery - having hope and the opportunity to regain control of their lives was vital. The Report suggested that in a consumer and family-driven system, consumers should choose their own programs and the providers that will help them most. However, current USA experience was that adults with serious mental illnesses and parents of children with serious emotional disturbances, typically have limited influence over the care they or their children receive.

The Commission argued that increasing opportunities for consumers to choose their providers, and allowing them to have greater control over funds spent on their care, should help to facilitate personal responsibility, create an economic interest in obtaining and sustaining recovery, and shift the incentives towards a system that promotes learning, self-monitoring, and accountability. Where a range of services are available, increased opportunities for choice would create a more viable marketplace for mental health care and provide a greater level of satisfaction by

giving consumers and families control. Increasing choice protected individuals and encourages quality.

It also argued that without choice and the availability of acceptable treatment options, people with mental illnesses were unlikely to engage in treatment or to participate in appropriate and timely interventions. Thus, giving consumers access to a range of effective, community-based treatment options is critical to achieving their full community participation. To ensure this access, the Commission called for community-based treatment options to be expanded, in particular for children and young people with serious emotional disorders. It argued that consumer needs and preferences should drive the type and mix of services provided, and should take into account the developmental, gender, linguistic, or cultural aspects of providing and receiving services. Each consumer or child's family should receive the assistance necessary to develop individual care plans.

The US Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA, www.samhsa.gov) has a mission 'to build resilience and facilitate recovery for people with or at risk for substance abuse and mental illness.' In collaboration with individual States it has identified ten domains as its National Outcome Measures (NOMs) to 'embody meaningful, real life outcomes for people who are striving to attain and sustain recovery, build resilience, and work, learn, live, and participate fully in their communities'. None of these measures specifically refer to choice, though they do cover increased access to services and client perception of care. In commenting on the New Freedom Commission's work, SAMHSA has pointed out that individuals may find that many treatments and services are simply unavailable, especially in rural areas - in other words, choice is restricted by limited resources.

The National Mental Health Association (NMHA, www.nmha.org) is a non-profit mental health organization, with more than 340 affiliates nationwide. Its website states that all consumers, parents and families are unique and essential participants in providing advocacy, services, education, and training, and all people should have access to a full array of high quality, community-based, culturally competent, integrated mental health services, regardless of ability to pay. Under a section on consumer advocacy, its website has advice for consumers about advance directives (including a toolkit) and how to challenge an insurance company/service provider decision to limit a treatment plan in order to obtain the treatment of their choice. The website also provides links under 'Treatment Resources and Support Groups', designed to help people choose a therapist and better understand treatment options.

The National Alliance on Mental Illness (NAMI, www.nami.org), 'The nation's voice on mental illness', has published a number of papers which include consideration of consumer choice. For example, *Access to Effective Medications* states that professional judgment and informed consumer choice should determine the choice of medications to treat mental illnesses. Choice should be based on current knowledge of effectiveness and potential side effects and should be consistent with existing treatment guidelines. *Legal Protections and Advocacy Strategies* suggests that Managed Care Organisations can maintain limited provider networks in the

interests of keeping administrative costs down, at the expense of offering consumers a meaningful choice of mental health care providers.

Overall, choice is clearly seen by the USA government as being a driver in the market to improved quality of services, a view echoed in the Westminster government's choice agenda for the NHS. However the evidence from the USA suggests that although it is accepted that consumer needs and choice should drive mental health service provision, in reality limitations on the range of services available and the sheer complexity and lack of coordination between different agencies (statutory, voluntary and private) leads to significant problems for consumers in making meaningful choices about their care.

New York

The New York Office of Mental Health has commissioned and published a White Paper on recovery-based principles, largely based on a consumer perspective (*Infusing Recovery-Based Principles into Mental Health Services: A White Paper by People who are New York State Consumers, Survivors, Patients and Ex-Patients*, September 2004).

This paper sets out, in prioritised order, a list of the ten rules for Quality Mental Health Services in New York State. Rule Number One, at the very top of the list, is 'There must be Informed Choice'. This rule is worth quoting in detail:

'Our collective definition of informed choice is best stated as obtaining useful information from the practitioner or professional and then deciding individually or collaboratively on the best course of action that promotes independence, recovery and an improved quality of life. This means that the professional must be knowledgeable and exhibit flexibility and openness toward information related to recovery, which may include treatment programs or treatment options that are holistic or services that are complementary to traditional treatment. This would include benefits and possible pitfalls to any treatment.'

Informed choice includes an educational approach to medications and side effects on behalf of all parties so that sound knowledgeable risk can be decided upon by us or collaboratively with the family, friends and/or our practitioners. This issue of medication is extremely important to those of us involved in the dialogues as the current status of medication administration is mostly seen as coercive and forceful and offers little or no information on what medications are doing to us beyond the treatment of symptoms. Medication education for prescribers, practitioners, therapists and peers is of the utmost importance and must be a priority. Informed choice cannot be exercised without accurate information.'

Many of us are quite capable of making decisions even if we are experiencing a severe emotional state of mind or presence. A system that promotes recovery would have genuine informed choice as the foundation of its service delivery. We also feel that informed choice must be a part of goal setting. Service planning that is built upon a foundation of informed choice should take

into account the whole person, not just the mental health-related symptoms. For example, spirituality, cultural background, physical well-being, community connections and social supports are essential considerations.

On a final note, a system that truly values informed choice will assure that each person who walks through the doors of the program is offered education on Advance Directives. Additionally, if someone within the program or service has an Advance Directive, the contents of that document would be respected and valued as a legitimate statement of the person's treatment decisions.'

A perspective from New York - John Allen

John Allen (Director, Bureau of Recipient Affairs at the New York Office of Mental Health, and one of the White Paper's commissioners) suggests there are five key issues around choice:

- balancing choice with protection. Families and services can have concerns that individuals lack the ability to make even basic choices. Even simple learning opportunities for someone to make a poor choice and then learn from the experience is often limited or protected against in favour of keeping the individual safe from possible negative consequences;
- informed choice. How much information (particularly when it comes from consumer literature or anecdotal experience rather than academic research) should individuals have, given that few have the time or resources to gather all of the relevant information before making a choice? Most choices in life are made with relatively easily available information - on subjects like ECT, such information that is well researched is biased in favour of the treatment. The little literature about how balanced information can be given within the time frames for decision making;
- most individuals make decisions based on their current knowledge and frame of reference. Individuals who have larger frames of reference (more collective experiences with exposure to a wide variety of alternatives) have greater ability to create choices by combining existing options or creating new variants. Individuals with limited frames of reference (e.g. those who have only experienced one type of service) will likely continue to choose the only option they know or, in the case of options they do not like, the only other option available;
- consumers' capacity and clinical alliance. Many psychiatrists have limited tolerance of collaboration around medication, citing their professional training or lack of capacity of the individual to make their own decisions. Some physicians impose medications (sometimes through court ordered processes) where the consumer has identifiable concerns regarding medication in general or the specific medication proposed. Clinical alliance - a core concept of clinical psychiatry - seems to often be lost. By promoting the building of clinical alliances between clinicians and individuals who use services, real opportunities can be created for individuals to participate as partners in treatment, making real choices as part of a shared decision making structure;

- creating opportunities for consumers to make and practice choices can be a time consuming process, which often service providers will say they do not have the staffing or funding to facilitate. In inpatient settings, almost all choices are pre-made for individuals, creating institutionalisation. Choices about even simple things that will enable an individual to survive in the community, like what time to go to bed and what time to wake up, are structured in favour of staff scheduling and operational convenience.

With respect to tools that help facilitate choice, John Allen believes that role modelling by using peers in service provision can be used to expand a consumer's frame of reference and reinforce alternative choices as real possibilities. Advance directives can help facilitate choice, but if clinicians use professional judgment to override an advance directive, they may also re-enforce that the individual is only given the appearance of making real choices. Crisis planning, advance directives and Wellness Recovery Action Plans (WRAP) are some of the current best practices for choice.

11.6 Canada

Canada remains one of the only developed countries without a formal national mental health strategy in place, although the federal Minister of Health has recently announced the establishment of a Commission on Mental Health and Mental Illness. Provincial and territorial governments have primary jurisdiction for the planning and delivery of mental health services in Canada.

The Public Health Agency of Canada (www.phac-aspc.gc.ca) on behalf of the federal government, has published a number of documents around mental health that touch on choice. For example, *Mental Health Promotion For People With Mental Illness - A Discussion Paper* (2002) pointed to research on recovery showing the importance of choices in a person's life, and stated that the purpose of mental health promotion for people with mental illness is to ensure that they have power, choice, and control over their lives and mental health.

The Agency's *Best Practices in Mental Health Reform: Discussion Paper* (1997) pointed out that, at that time, the introduction of competition among provider agencies as a fiscal mechanism to improve quality and efficiency had had disappointing results in the US and UK. In order to make informed choices you needed information available to consumers and a feasible set (at least 3 or 4) of alternative providers who can deliver the required service. The Paper also refers, in respect to supported employment, to research findings which suggested that if clients are given adequate information about programs and services, they will be able to make appropriate choices.

The Canadian Mental Health Association (CMHA) (www.cmha.ca) promotes the mental health of all Canadians and supports the recovery of people experiencing mental illness through advocacy, education, research and service. Its principles include empowerment and participation in decision-making.

A number of CMHA documents touch on choice. A paper on *Community Committal*, looking at compulsory community treatment in Canada, quotes the Canadian Charter of Rights and Freedom ('Every individual is equal before and under the law and has the right to equal protection and equal benefits of law without discrimination'), and states that all Canadian citizens, including those with a mental illness, should have the right to make choices about whether or not to receive treatment, within the bounds of their respective mental health acts. The paper also points out that opponents of community committal believe that it denies people the basic right to choose or refuse treatment, and refers to advance directives as a way of enhancing the possibility for choice.

The CMHA's *Framework for Support* (third version published in 2004) recognises that the consumer's interests and choices must remain at the centre of concern. *Housing for Persons with Mental Disabilities* (1999) states that people are entitled to choose whatever type of housing they want, as well as where to live, whom to see, and how to behave in their home. This depends on the availability of different types of housing within all residential areas of a community. The housing choices of those with mental disabilities should be as varied and attractive as those of all citizens. The person with the disability should be seen as the primary decision-maker with respect to housing choices, with assistance, if required, from his or her personal support network. In *Steps to Employment: A Workbook for people with mental health problems* (undated, and no longer available on the CMHA website) advice is given about whether to choose to disclose an individual's mental health status to an employer.

A perspective from Canada - Penny Marrett

Penny Marrett, Chief Executive Officer of the Canadian Mental Health Association, highlights four key points in respect of choice in mental health:

- there can be no choice without individuals having all the information required to make the decisions that are considered best for themselves;
- choice includes being an active member of a team, not simply a passive recipient of services;
- it is essential that individuals should be supported in the decisions that they make in their journey towards recovery;
- community supports are required to enable choice for people experiencing mental illness, not only with respect to healthcare but also to decisions about everyday life.

12 Conclusions

Making choice a reality is no easy task, but it is essential if mental health service users are genuinely to be placed at the centre of a Patient-led NHS, as the government intends. The remit of this review was to provide a comprehensive overview of the literature to inform the NIMHE Choice Steering Group in developing a choice strategy for people who use mental health services. The review aimed to identify what tools, media and methods were available to enable those with mental health problems and their carers make meaningful choices about their care. Part of the remit also included literature relating to life choices, access and engagement, assessment and care pathways.

We found a great deal of literature relating to the choice issue published in the last five years. However, there was relatively little literature specifically couched in terms of life choices, access and engagement, assessment and care pathways in relation to choice, hence our decision to focus on the emerging themes from the literature. The examples of good practice described provide a rich source of information and guidance on media, tools and methods to enable service users and carers to make meaningful choices about their care and treatment.

The main literature review highlights what is already known about the challenges and pitfalls to enable choice such as:

- professionals' reluctance in allowing service users to make choices where they differ from their own;
- the lack of accessible information about choice options for service users and carers;
- the lack of treatment and medication choices, and alternatives to the medical model of care;
- issues of capacity and decision-making for some groups; and
- service users' perception that they are often not listened to about what they want in their lives.

Other significant issues arising from the literature include:

- the lack of carer involvement in choice decisions;
- little, if any, specific literature about choices for people with mental health problems in prison and forensic services;
- service users' scepticism that they have a real choice;
- existing gaps in the current mental health services such as restricted local service provision that makes choice meaningless, the lack of information on medication, and partial implementation of the CPA
- the value of advance directives; and
- the choice benefits that could come from expanding direct payments to mental health service users, so long as potential risks are managed.

This is, however, by no means the full picture. This review also pulls together a considerable amount of further information to suggest ways that the choice agenda

can be taken forward. In ensuring that choice works several prerequisites are necessary including:

- a commitment to partnership working between service users, carers and professionals, including meaningful involvement and empowerment;
- in particular, there needs to be a focus on traditionally excluded groups such as people from BME communities, homeless people and people in contact with the criminal justice system;
- training for professionals to support service users and carers make choices - such support came across as crucial;
- the provision of easily accessible and understandable information of the right kind, in the right format, at the right time;
- adequate funding to allow a range of local service options to be available to service users; and
- wider availability of advance directives and direct payments.

From all this, we conclude that although choice is by no means a reality for many who use mental health services (and the UK is not alone in this) there are clear benefits for service users in pushing forward efforts to increase the choices they have.

The Review uncovers many examples of good practice. The opportunity exists to study these and understand better how mental health service users are benefiting from being empowered to make decisions about both their health care and life choices.

We conclude that the challenge for everyone involved in mental health, from government ministers to front-line staff, is to ensure that there is both the will and the resources made available to replicate this good practice more widely. Choice clearly has a central role to play if we are to improve the daily experience of people with mental health problems and support them on the road to recovery.

Mental health has often been referred to as the 'Cinderella service' within the NHS. Equality will only come if mental health service users are offered the same choices about their care as people with physical health needs. We hope this review will help turn that aspiration into a reality by applying many of the key findings and issues from the research and other literature into service development and practice.

13 References

- Abulseoud O, Fayek M *et al.* (2002) Patients' preference for conventional antipsychotic medications. *Psychiatric Services*, 53, 5, 537-8 & 547.
- Advocacy in Somerset. (2005) *Headspace Toolkit*. Taunton: Advocacy in Somerset. From: <http://www.headspacetoolkit.org/>
- Age Concern. (2003) *Advance statements, advance directives and living wills. Information sheet, Ref IS/5*. London: Age Concern. From: www.ageconcern.org.uk
- Allegheny County Department of Human Services. (2003) *Taking charge of your child's mental health: A parent's guide*. Allegheny County Department of Human Services, Office of Behavioral Health, Bureau of Child and Adolescent Services. From: <http://www.county.allegheny.pa.us/dhs/AboutDHS/about-DHS.html>
- Allison S *et al.* (2004) *Carers and confidentiality in mental health. Issues involved in information sharing*. London: Royal College of Psychiatrists. From: www.partnersincare.co.uk
- Alzheimer's Society. (2002) *Future medical treatment: advance statements and advance directives or living wills. Information sheet*. London: Alzheimer's Society. From: <http://www.alzheimers.org.uk/>
- Amering M, Stastny P & Hopper K. (2005) Psychiatric advance directives: qualitative study of informed deliberations by mental health service users. *British Journal of Psychiatry*, 186, 247-52.
- Appelbaum P. (2004) Law & psychiatry. Psychiatric advance directives and the treatment of committed patients. *Psychiatric Services*, 55, 7, 751-2, 763.
- Appleby J. *et al.* (2003) Patients choosing their hospital. *British Medical Journal*, 326, 407-8.
- Appleby J & Dixon J. (2004) Patient choice in the NHS. *British Medical Journal*, 329, 61-61.
- Ashley P & Schofield J. (2002) How to plan your own future dementia care. *Journal of Dementia Care*, 10; 2, 20-2.
- Atkinson J. (2004) Ulysses' crew or Circe?: the implications of advance directives in mental health for psychiatrists. *Psychiatric Bulletin*, 28, 1, 3-4.
- Atkinson J *et al.* (2003a) Issues in the development of advance directives in mental health care. *Journal of Mental Health*, 12, 5, 463-74.
- Atkinson J *et al.* (2003b) The development of potential models of advance directives in mental health care. *Journal of Mental Health*, 12, 6, 575-584.

Atkinson J & Garner H . (2002) Least restrictive alternative - advance statements and the new mental health legislation. *Psychiatric Bulletin*, 26, 7, 246-7.

Atkinson J *et al.* (2005) *Mental health law in Scotland. Review of the literature relating to mental health legislation.* Edinburgh: Scottish Executive Social Research.

Audit Commission. (2002-2003) *All Our Lives: Social care in England.* Audit Commission.

Avon, Somerset and Wiltshire Cancer Services Network. (2003) *Developing and evaluating best practice in user involvement in cancer services. Final Report.* From: www.aswcs.nhs.uk/DoH/Finalreport/FinalReport.pdf

Avon, Somerset and Wiltshire Cancer Services Network. (2005) User Involvement Newsletter. Issue 15, October.
From: www.aswcs.nhs.uk/userinvolvement/uig/newsletters/Oct05.pdf

Bakker A, Spinhoven P *et al.* (2000) Cognitive therapy by allocation versus cognitive therapy by preference in the treatment of panic disorder. *Psychotherapy and Psychosomatics*. 69, 240-243.

Bamforth M. (2005) *A checklist for parents with children with mental health problems.* London: Royal College of Psychiatrists. From: <http://www.partnersincare.co.uk>

Banks D, Burdett J, Burnett V *et al.* (2004) (2004) *Our lives in 2014: a recovery vision from people with experience of mental illness for the second mental health plan and the development of the health and social sectors.* New Zealand: Mental Health Commission. From: [http://www.mhc.govt.nz/publications/2004/MCH_Our_Lives_Final\(b\).pdf](http://www.mhc.govt.nz/publications/2004/MCH_Our_Lives_Final(b).pdf)

Barnes M, Harrison S, Mort M, & Shardlow P. (1999) *Unequal Partners - User groups and community care.* Bristol: The Policy Press.

Bazelon D. (2003) *Psychiatric Advance Directives. Forms to prepare an advance directive for mental health decision making.* Washington D.C., Bazelon Center for Mental Health Law. From: <http://www.bazelon.org/>

Beamer S, with Brookes M. (2001) *Making decisions: best practice and new ideas for supporting people with high support needs to make decisions.* London: Values into Action.

Beever A. (2002) *Advance statements in mental health. Updates Research and Policy Briefings from the Mental Health Foundation, 4, 4.* September. London: Mental Health Foundation.

Bell S. (2003) Advance directives and mental health consumers. *Incite*, 2, 1, 24-31.

- Beresford P & Hopton J. (2001) Whose service is it anyway? *Openmind*, 104, 10-11. July & August.
- Bewley C. (2000) Vital lessons to be learned from the South Lanarkshire ruling. *Community Living*, 13, 4, 9-11. April & May.
- Bewley C & McCulloch L. (2004) *Helping ourselves? Direct payments and the development of peer support for people with learning difficulties: a report commissioned by the Joseph Rowntree Foundation and produced by Values into Action*. London: Values into Action.
- Bhugra D, Harding C & Lippett R. (2004) Pathways into care and satisfaction with primary care for black patients in South London. *Journal of Mental health*, 13, 2, 171-183.
- Billcliff N, McCabe E, & Brown K. (2001) Informed consent to medication in long-term psychiatric in-patients. *Psychiatric Bulletin*, 25, 4, 132-134.
- Bolzan N & Gale F. (2002) The citizenship of excluded groups: challenging the consumerist agenda. *Social Policy & Administration*, 36, 4, 363-375.
- Bowey L & McGlaughlin A, with Saul C. (2005) Assessing the barriers to achieving genuine housing choice for adults with a learning disability: the views of family carers and professionals. *British Journal of Social Work*, 35, 1, 139-148.
- Boyle K & Jenkins C. (2002) *Housing for Londoners with Mental Health Problems*. London: King's Fund.
- Bradstreet S. (2004) All you need to know? *Mental Health Today*, 27-30. May.
- British Institute of Learning Disabilities. (2003) *Journey to Independence. How to run your life with direct payments*. Kidderminster. British Institute of Learning Disabilities.
- Bungay H & Alaszewski A. (2003) Handle with care. *Health Service Journal*, 113, 5866, 28-29.
- Burnham D. (2001) Ticket to ride. *Community Care*, 24-25. 8 February.
- Calsyn R, Morse G *et al.* (2003) Client choice of treatment and client outcomes. *Journal of Community Psychology*, 31, 4, 339-348.
- Calsyn R, Winter J & Morse G. (2000) Do consumers who have a choice of treatment have better outcomes? *Community Mental Health Journal*, 36, 2, 149-60.
- Cameron L & Murphy J. (2002) Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities*, 30, 105-112.

Campbell C, Cornish F, & Mclean C. (2004) Social capital, participation and the perpetuation of health inequalities: obstacles to African-Caribbean participation in 'partnerships' to improve mental health. *Ethnicity & Health*, 9, 4, 313-35.

Campbell P. (2001) The role of users of psychiatric services in service development - influence not power. *Psychiatric Bulletin*, 25, 3, 87-8.

Cantley C *et al.* (2005) *Listen to us: involving people with dementia in planning and service development*. Newcastle upon Tyne: Dementia North and Northumbria University.

Care Services Improvement Partnership. (2005a) *Our choices in mental health*. London: Care Services Improvement Partnership.

Care Services Improvement Partnership (2005b) *Choices checklist*. London: Care Services Improvement Partnership.

Carlson T. (2002) Right for the job. *Learning Disability Practice*, 5, 8, 12-5.

Carpenter J, Schneider J *et al.* (2004) Integration and targeting of community care for people with severe and enduring mental health problems: users' experiences of the care programme approach and care management. *British Journal of Social Work*, 34, 3, 313-333.

Carr S. (2004) *Has service user participation made a difference to social care services? Position Paper No 3*. London: Social Care Institute for Excellence.

Carr S. (2005) *Consultation Response. Independence, well-being and choice: our vision for the future of social care for adults in England*. London: Social Care Institute for Excellence.

Cea C & Fisher C. (2003) Health care decision-making by adults with mental retardation. *Mental Retardation*, 41, 2, 78-87.

Center for Medicare and Medicaid Services. (undated) *Informational website on the 'Ticket to Work and Work Incentives Improvement Act of 1999'*. USA: Center for Medicare and Medicaid Services. At: <http://www.cms.hhs.gov/twwia/>

Children's Rights Alliance for England. (2005) *Ready Steady Change. Training and tools to put children's and young people's wishes, feelings and ideas at the centre of public services*. London: Children's Rights Alliance for England. From: <http://www.crae.org.uk/>

Claassen C, Hughes C *et al.* (2000) The nature of help-seeking during psychiatric emergency service visits by a patient and an accompanying adult. *Psychiatric Services*, 51, 7, 924-7.

- Clare L & Cox S. (2003) Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability & Society*, 18, 7, 935-53.
- Clark C & Krupa T. (2002) Reflections on empowerment in community mental health: giving shape to an elusive idea. *Psychiatric Rehabilitation Journal*, 25, 4, 341-9.
- Cobb A, Darton K & Juttla K. (2001) *Mind's yellow card for reporting drug side effects: a report of users' experiences*. London: Mind.
- Coldham T & Spandler H. (2005) Making choices and taking control. *Openmind*, 132, 18-19. March & April.
- Collins J. (2002) Direct payments need the Scottish treatment. *Care Plan*, 8, 4, 12-15.
- Commission for Social Care Inspection. (2004) *Direct payments. What are the barriers?* London: Commission for Social Care Inspection.
- Commission for Social Care Inspection. (2005) *The state of social care in England 2005-05*. London: Commission for Social Care Inspection.
- Cooper K & Browder D. (2001) Preparing staff to enhance active participation of adults with severe disabilities by offering choice and prompting performance during a community purchasing activity. *Research in Developmental Disabilities*, 22, 1-20.
- Copeland M. (undated) *Mental Health Recovery including Wellness Recovery Action Planning*. From: http://www.mentalhealthrecovery.com/art_wrap.html
- Copeland. (undated) *Guide to Developing a WRAP Wellness Recovery Action Plan*. From: <http://www.healthyplace.com/communities/depression/mhrecovery/articles7.asp>
- Crawford M *et al* (2002) Systematic review of involving patients in the planning and development of health care, *British Medical Journal*, 325, 30 &1263. November
- Crawford M, Ellis E, Gibbon R & Waters H. (2004) In hospital, at home, or not at all: a cross-sectional survey of patient preferences for receipt of compulsory treatment. *Psychiatric Bulletin*, 28, 10, 360-363.
- Crouch D. (2003) 'I give clients more power'. *Nursing Times*, 99, 34, 38-39.
- Dace E. (2001) Telling it like it is... A cat among the pigeons'. *Mental Health Today*, 29-31. December.
- Danagher N. (2003) From the margins to the mainstream. *Learning Disability Practice*, 6, 1, 18-20.

Daniel K. (2004) The Friday Group. *Community Practitioner*, 77, 9, 329-330.

Darton K. (2005) *Making sense of coming off psychiatric drugs*. London: Mind.
From: www.mind.org.uk

Davidson D & Vick N. (2002) Beyond involvement: making choices and taking control. *Mental Health Review*, 7, 2, 25-28.

Davidson D & Luckhurst L (eds). (2002) *Making choices, taking control. Direct payments and mental health service users/survivors*. National Centre for Independent Living. (First published by Joseph Rowntree Foundation.)

Davidson L. (2005) Recovery, self management and the expert patient: changing the culture of mental health from a UK perspective. *Journal of Mental Health*, 14, 1, 25-35.

Dawson J, Romans S *et al.* (2003) Ambivalence about community treatment orders. *International Journal of Law and Psychiatry*, 26, 243-255.

de Haan L, van Raaij B, van den Berg R *et al.* (2001) Preferences for treatment during a first psychotic episode. *European Psychiatry*, 16, 2, 83-9.

Department of Health. (1990a) *Caring for People. The Care Programme Approach for people with a mental illness referred to specialist mental health services*. Joint Health/Social Services Circular. C(90)23/LASSL(90)11.

Department of Health. (1990b) *The NHS and Community Care Act*. London: Stationary Office.

Department of Health (1999) *National Service framework for Mental Health*. London: Department of Health.

Department of Health. (2000) *The NHS Plan: a plan for investment, a plan for reform*. London: Department of Health.

Department of Health. (2001a) *Treatment choice in psychological therapies and counselling; evidence based clinical practice guideline; brief version*. London: Department of Health.

Department of Health. (2001b) *The expert patient: a new approach to chronic disease management for the 21st century*. London: Department of Health.

Department of Health. (2001c) *Valuing people; a new strategy for learning disability for the 21st century*. London: Department of Health.

Department of Health. (2001d) *Valuing people: a new strategy for learning disability for the 21st century: planning with people towards person centred approaches: guidance for implementation groups*. London: Department of Health.

Department of Health. (2001e) *Nothing about us without us. Report of the Service Users Advisory Group.* London: Department of Health.

Department of Health. (2003a) *Developing choice, responsiveness and equity in health and social care. A national consultation exercise.* London: Department of Health.

Department of Health. (2003b) *Building on the Best. Choice, responsiveness and equity in the NHS.* London: Department of Health.

Department of Health. (2004a) *Choose and book: patients' choice of hospital and booked appointment.* London: Department of Health.

Department of Health. (2004b) *Choosing health: making healthy choices easier.* London: Department of Health.

Department of Health. (2004c) *Direct Choices. What councils need to make direct payments happen for people with learning disabilities.* London: Department of Health.

Department of Health. (2004d) *A guide to receiving direct payments from your local council. A route to independent living.* Department of Health.

Department of Health. (2004e) *Draft Mental Health Bill.* London: Department of Health.

Department of Health. (2004f) *The National Service Framework for Mental Health - Five Years On.* London: Department of Health.

Department of Health. (2005a) *Creating a Patient-led NHS. Delivering the NHS Improvement Plan.* London: Department of Health.

Department of Health. (2005b) *Delivering Choosing Health: making healthier choices easier.* London: Department of Health.

Department of Health. (2005c) *Independence, Well-being and Choice. Our vision for the future of social care for adults in England.* London: Department of Health.

Department of Health. (2005d) *Responses to the consultation on adult social care in England. Analysis of feedback from the Green Paper Independence, Well-being and Choice.* London: Department of Health.

Department of Health. (2005e) *Supporting people with long term conditions. An NHS and social care model to support local innovation and integration.* London: Department of Health.

Department of Health. (2005f) *Older and disabled people to receive virtual money box.* London: DH Press Release, 21 November 2005.

Department of Health and National Institute for Mental Health. (2005g) *Mental health and deafness. Towards equity and access. Best practice guide*. London: Central Office of Information.

Department for Constitutional Affairs. (2003) *Draft Mental Incapacity Bill*. London: Stationary Office.

Department for Constitutional Affairs. (2005) *Mental Capacity Act*. London: Stationary Office.

Department for Education and Skills and Department of Health. (2004) *National service framework for children, young people and maternity services. The mental health and psychological well-being of children and young people*. London: Department for Education and Skills and Department of Health.

Derbyshire Mental Health Services NHS Trust. (2004) *Guidelines for people making an Advance Directive*. Derbyshire Mental Health Services NHS Trust.

Derbyshire Mental Health Services NHS Trust. (undated) *Writing Good Care Plans. A good practice guide, Draft 3*. Derbyshire Mental Health Services NHS Trust.

Dewar B, Goulbourne A, Irvine L & Riddell H. (2002) The carer's role in planning care for people with dementia. *Professional Nurse*, 17, 5, 318-21.

Dewing J. (2001) Older people with mental illness and administration of medicines: consent and capacity. *Mental Health Practice*, 5, 4, 33-38.

Dow J. (2004) Direct payments. *Journal of Integrated Care*, 12, 2, 20-23.

Dowson S. (2002) *Not just about the money: reshaping social care for self-determination*. Bury St. Edmunds: Community Living & Emprise International Training and Consultancy.

Duffy S et al. (2004) *In Control. A national programme to change the organisation of social care in England so that people who need support can take more control of their own lives and fulfil their role as citizens*. In Control. From: www.in-control.org.uk

Duffy S. (2004) *In Control. The Model Self-Directed Support Policy, Version 2.2*. In Control. From: www.in-control.org.uk

Duffy S. (2005a) In control, *Community Connecting*, Issue 1,10-11.

Duffy S. (2005b) Will 'In Control' at last put people in charge of their lives?. *Community Living*, 18, 4, 10-13.

Duffy S. (2005c) *In Control. An exploration of the advantages of individual budgets for disabled people and some of the challenges of implementation issues*. In Control. From: www.in-control.org.uk

- Duffy S. (2005d) *In Control's response to the green paper Independence, Well-being and Choice*. In Control. From: www.in-control.org.uk
- Duke University Program on Psychiatric Advance Directives. (undated) *Psychiatric Advance Directives Toolkit for Consumers*. From <http://pad.duhs.duke.edu/>
- Dupree L, Watson M & Schneider M. (2005) Preferences for mental health care: a comparison of older African Americans and older Caucasians. *Journal of Applied Gerontology*, 24, 3, 196-210.
- Dwight-Johnson M, Unutzer J *et al.* (2001) Can quality improvement programs for depression in primary care address patient preferences for treatment? *Medical Care*, 39, 9, 934-44.
- Edge J. (2001) *Who's in control: decision-making by people with learning difficulties who have high support needs*. London: Values into Action.
- Eisen S, Dickey B & Sederer L. (2000) A self-report symptom and problem rating scale to increase inpatients' involvement in treatment. *Psychiatric Services*, 51, 3, 349-53.
- Evans C, Carmichael A *et al.* (2002) *Users' Best Value. A guide to user involvement good practice in Best Value reviews*. Joseph Rowntree Foundation, Wiltshire & Swindon Users' Network, and the University of Bath.
- Fajerman L, Jarrett M & Sutton F. (2001) *Children as Partners in Planning: A training resource to support consultation with children*. London: Save the Children. From: <http://www.savethechildren.org.uk/>
- Fajerman L, Treseder P & Connor J. (2005) *Children are service users too: a guide for consulting children and young people*. London: Save the Children. From: <http://www.savethechildren.org.uk/>
- Farrington-Douglas J & Allen J. (2005) *Equitable choices for health*. London: Institute for Public Policy Research.
- Faulkner A & Layzell S. (2000) *Strategies for Living: a report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.
- Faulkner A & Williams K. (2005) *Future Perfect. Mental health service users set out a vision for the 21st century*. London: Rethink.
- Feinberg L & Whitlatch C. (2002) Decision-making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 17, 4, 237-44.
- Feinberg, L & Whitlatch C. (2001) Are persons with cognitive impairment able to make consistent choices? *The Gerontologist*, 41, 3, 374-382.

- Fernando S. (2005) Backing user choice. *Openmind*, 131, 6-7. January & February.
- Ferns P. (2002) *Finding a way forward - a Black perspective on social model approaches to mental health services*. In, *Start Making Sense... developing social models to understand and work with mental distress*. Notes from SPN study day 11 November 2002. SPN Paper 3. London: Social Perspectives Network. From: www.spn.org.uk
- Finfgeld D. (2004) Empowerment of individuals with enduring mental health problems: results from concept analyses and qualitative investigations. *Advances in Nursing Science*, 27, 1, 44-52.
- Flynn M, Keywood K & Fovargue S. (2003) Warning: health choices can kill. *Journal of Adult Protection*, 5, 1, 30-34.
- Forrest E. (2004) The right to choose. *Health Service Journal*, 114, 5935, 24-26.
- Forrest S, Risk I, Masters H & Brown N. (2000) Mental health service user involvement in nurse education: exploring the issues. *Journal of Psychiatric & Mental Health Nursing*, 7, 1, 51-7.
- Fovargue S, Keywood K & Flynn M. (2000) Participation in health care decision-making by adults with learning disabilities. *Mental Health & Learning Disabilities Care*, 3, 10, 341-4.
- Fox E. (2004) Choice and control. *Mental Health Review*, 9, 1, 25-27.
- Freedman R & Boyer N. (2000) The power to choose: supports for families caring for individuals with developmental disabilities. *Health & Social Work*, 25, 1, 59-68.
- Fulford M & Farhall J. (2001) Hospital versus home care for the acutely mentally ill? Preferences of caregivers who have experienced both forms of service. *Australian and New Zealand Journal of Psychiatry*; 35, 5, 619-25.
- Geller J. (2000) The use of advance directives by persons with serious mental illness for psychiatric treatment. *Psychiatric Quarterly*, 71, 1, 1-13. Spring.
- Genovich-Richards J & Wyzkiewicz J. (2002) Consumers: from perceptions to participation. *Journal of Healthcare Quality*, 24, 6, 39-41, 53.
- George C. (2004) What chance choice? *Mental Health Today*, September, 12-13.
- George C. (2005) Talk to the hand. *Mental Health Today*, June, 8-9.
- Gibbs A, Dawson J *et al.* (2004) Maori experience of community treatment orders in Otago, New Zealand. *Australian & New Zealand Journal of Psychiatry*, 38, 830-835.

- Gibbs A, Dawson J *et al.* (2005) How patients in New Zealand view community treatment orders. *Journal of Mental Health*, 14, 4, 357-368.
- Glasby J. (2002) Nothing about us without us. *Learning Disability Practice*, 5, 10, 19.
- Goldsack S *et al.* (2005) *Experiencing a recovery-oriented acute mental health service: home based treatment from the perspectives of service users, their families and mental health professionals*. Wellington, New Zealand: Mental Health Commission.
- Gorfin L & McGlaughlin A. (2003) Housing for adults with a learning disability: 'I want to choose, but they don't listen'. *Housing Care and Support*, 6, 3, 4-8.
- Gramlich S, McBride G, Snelham N *et al.* (2002) *Journey to Independence: What self advocates tell us about direct payments*. Kidderminster. British Institute of Learning Disabilities. From: <http://www.bild.org.uk>
- Gray R & McAnespie L. (2004) Consulted or excluded? *Learning Disability Practice*, 7, 6, 30-2.
- Green C. (2000) Mental health care and human rights. *Mental Health Practice*, 4, 4, 8-10.
- Green C, Middleton S & Reid D. (2000) Embedded evaluation of preferences sampled from person-centered plans for people with profound multiple disabilities. *Journal of Applied Behavior Analysis*, 33, 4, 639-42.
- Hall P, Trees C *et al.* (2002) Learning to choose food and drink. *Nursing Times*, 98, 10.
- Hamann J, Cohen R *et al.* (2005) Do patients with schizophrenia wish to be involved in decisions about their medical treatment? *American Journal of Psychiatry*, 162, 2382-2384.
- Hansen T, Hatling T *et al.* (2004) The user perspective: Respected or rejected in mental health care? *Journal of Psychiatric & Mental Health Nursing*, 11, 3, 292-297.
- Harris J. (2003) Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*, 31, 1, 3-8.
- Hatton C *et al.* (2004) The resident choice scale: a measure to assess opportunities for self-determination in residential settings. *Journal of Intellectual Disability Research*, 48, 2, 103-113.
- Healthcare Commission. (2005) *Survey of users 2005, Mental Health Services*. London: Healthcare Commission. From: http://www.healthcarecommission.org.uk/NationalFindings/Surveys/PatientSurveys/fs/en?CONTENT_ID=4018286&chk=F5hJwR

- Hebron C. (2004) Spoilt for choice? *Learning Disability Practice*, 7, 4, 10-4.
- Heller T, Miller A, Hsieh K & Sterns H. (2000) Later-life planning: promoting knowledge of options and choice-making. *Mental Retardation*, 38, 5, 395-406.
- Henderson C, Flood C *et al.* (2004) Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial. *British Medical Journal online*, doi:10.1136/bmj.38155.585046.63. From: <http://bmj.bmjournals.com/>
- Hertfordshire Partnership NHS Trust. (undated) *The Advance Directive. Making your wishes known*. From: www.hertsparts.nhs.uk/mh/advanced.htm
- Heslop P. (2005) *Direct Payment for Mental Health Users/Survivors. A guide to some key issues*. London: National Centre for Independent Living.
- Heslop P, Folkes L & Rodgers J. (2005) The knowledge people with learning disabilities and their carers have about psychotropic medication. *Learning Disability Review*, 10, 4, 10-18.
- Hird M & Cash K. (2000) Power play. *Openmind*, 101,12-13. January & February.
- Hirschman K, Xie S *et al.* (2004) How Does an Alzheimer's Disease Patient's Role in Medical Decision Making Change Over Time? *Journal of Geriatric Psychiatry & Neurology*, 17, 2, 55-60.
- Hogman G & Sandamas G. (2001) *A Question of Choice*. London: National Schizophrenia Fellowship.
- Holm S. (2001) Autonomy, authenticity, or best interest: everyday decision-making and persons with dementia. *Medicine, Health Care & Philosophy*, 4, 2,153-9.
- Holman A. (2002) Direct payments: commentary and review. *Tizard Learning Disability Review*, 7, 4, 17-20.
- Hope T. (2002) Evidence-based patient choice and psychiatry. *Evidence-Based Mental Health*, 5, 4, 100-101. From: www.ebmj.bmjournals.com
- Hopkinson P. (2003) *Advance Directives Policy*. Derbyshire Mental Health Services NHS Trust. December.
- Hopton J & Nolan P. (2003) Involving users in mental health services, *Mental Health Practice*, 6, 7, 14-18.
- Howatson J. (2005) Health action plans for people with learning disabilities. *Nursing Standard*, 19, 43, 51-7.
- Jackson C. (2004a) Why not? *Mental Health Today*, 12-13. February.

Jackson C. (2004b) Small changes, big difference. *Mental Health Today*, 16-17. July & August.

Jackson R. (2005) Desperate DAN: The disempowerment of people with learning disabilities through direct action. *British Journal of Developmental Disabilities*, 51(Pt1), 100, 103-107.

James A. (2002) Prescribing choices. *Openmind*, 115, 19. May & June.

Joshi K. (2003) Psychiatric advance directives. *Journal of Psychiatric Practice*, 9, 4, 303-6.

Joyce T & Shuttleworth L. (2001) From engagement to participation: how do we bridge the gap? *British Journal of Learning Disabilities*, 29, 2, 63-71.

Karlawish J, Casarett D *et al.* (2001) Relationship between Alzheimer's disease severity and patient participation in decisions about their medical care. *Journal of Geriatric Psychiatry & Neurology*, 15, 2, 68-72.

Keating F *et al.* (2002) *Breaking the Circles of Fear: A review of the relationship between mental health services and African and Caribbean communities*. London: Sainsbury Centre for Mental Health.

Keeton E & Goodman L. (2005) Choice in the diet of people with learning difficulties. *Nursing Times*, 101, 14.

Kennedy A, Gately C & Rogers A. (2004) *Assessing the process of embedding EPP in the NHS. Preliminary Survey of PCT Pilot Sites*. Manchester: National Primary Care Research and Development Centre.

Kent and Medway NHS. (undated) Guidelines for people wishing to make an advance directive for mental health. From: <http://www.kentandmedway.nhs.uk>

King N. (2003) Choice of where and how you live: how families can create new solutions to a familiar problem. *Housing Care and Support*, 6, 1, 27-32.

Kjellberg A. (2002) More or less independent. *Disability & Rehabilitation*, 24, 16, 828-40.

Kroese B & Holmes G. (2005) The use of psychotropic medication for people with learning disabilities. *Learning Disability Review*, 10, 4, 19-22.

Kruzich J, Jivanjee P *et al.* (2003) Family caregivers' perceptions of barriers to and supports of participation in their children's out-of-home treatment. *Psychiatric Services*, 54, 11, 1513-8.

Kurtz Z & James C. (2002) *What's New: Learning from the CAMHS Innovation projects. Summary*. London: Department of Health.

- Kurtz Z, Stapelkamp C *et al.* (2005) *Minority Voices: A guide to good practice in planning and providing services for the mental health of Black and minority ethnic young people*. London: Young Minds. From: <http://www.youngminds.org.uk>
- Lammers J & Happell B. (2004) Mental health reforms and their impact on consumer and carer participation: a perspective from Victoria, Australia. *Issues in Mental Health Nursing*, 25, 3, 261-76.
- Lasser K, Himmelstein D *et al.* (2002) Do minorities in the United States receive fewer mental health services than Whites? *International Journal of Health Services*, 32, 3, 567-78.
- Last A. (2003) Pick and choose. Involving service users in the selection of a manager for learning disabilities services. *Health Service Journal*, 113, 5852, 28-9.
- Latvala E, Saranto K & Pekkala E. (2004) Developing and testing instruments for improving cooperation and patient's participation in mental health care. *Journal of Psychiatric & Mental Health Nursing*, 11, 5, 614-9.
- Lawton A. (2002) Making choices to make changes, *Mental Health Today*, 18-21. July.
- Lawton-Smith S. (2002) Patient adherence with anti-depressant treatment. *British Journal of Psychiatry*, 181, 78.
- Layard R. (2004) *Mental Health: Britain's biggest social problem?* Paper delivered to the Cabinet Office. (unpublished)
- Learning Disabilities Association of America. (2005) *Preventing mental health problems: tips for parents of young children*. Learning Disabilities Association of America website at http://www.lidaamerica.us/aboutld/parents/mental_health/tips.asp
- Leece J. (2003) Trust in me - will user-independent trusts enable older people with dementia to access direct payments? *Generations Review*, 13, 4. October.
- Leeds CAMHS & Barnardos. (2005) *CAMHS user and carer participation*. From: <http://www.ru-ok.com/>
- Lehmann P. (2005) All about PSY DREAM. Psychiatric Drug Registration, Evaluation & All-Inclusive Monitoring. *Epidemiologia e Psichiatria Sociale*, 14, 1, 15-21.
- Lelliott P, Beevor A, Hogman G *et al.* (2001) Carers' and users' expectations of services - user version (CUES-U): a new instrument to measure the experience of users of mental health services. *British Journal of Psychiatry*, 179, 67-72.
- Lewis L. (2003) Is 'participation' all just rhetoric? *Mental Health Nursing*, 23, 6, 4-6.

- Lewis S. (2005) *Direct payments: answering frequently asked questions. Adult Services Resource Guide 05*. London: Social Care Institute for Excellence.
- Linhorst D & Eckert A. (2003) Conditions for empowering people with severe mental illness. *Social Service Review*, 77, 2, 279-305.
- Linhorst D, Hamilton G *et al.* (2002) Opportunities and barriers to empowering people with severe mental illness through participation in treatment planning. *Social Work*, 47, 4, 425-434.
- Llewellyn P. (2004) Nursing and advocacy in person centred planning. *Learning Disability Practice*, 7, 9, 14-17.
- Loughlin D, Simon-Rusinowitz L *et al.* (2004) Preferences for a cash option versus traditional services for Florida children and adolescents with developmental disabilities. *Journal of Disability Policy Studies*, 14, 4, 229-40.
- Lunt A. (2004) The implications for the clinician of adopting a recovery model: the role of choice in assertive treatment. *Psychiatric Rehabilitation Journal*, 28, 1, 93-7.
- McAllister M & Walsh K. (2004) Different voices; reviewing and revising the politics of working with consumers in mental health. *International Journal of Mental Health Nursing*, 13, 1, 22-32.
- McCann T & Clark E. (2004) Advancing self-determination with young adults who have schizophrenia. *Journal of Psychiatric & Mental Health Nursing*, 11, 1, 12-20.
- McGlaughlin A & Gorfin L with Saul C. (2004) Enabling adults with learning disabilities to articulate their housing needs. *British Journal of Social Work*, 34, 5, 709-726.
- McIntosh P. (2003) Issues of client examination: an imposition of power? *Nursing & Residential Care*, 5, 1, 36-8.
- McNally, S. (2002) A survey of self-advocacy groups for people with learning disabilities in an English region. *Journal of Learning Disabilities*, 6, 2, 185-195.
- Maglajlic R, Brandon D & Given D. (2000) Making direct payments a choice: a report on the research findings. *Disability & Society*, 15, 1, 99-113.
- Making Decisions Alliance. (2003) *Advance statements and advance directives*. From: www.makingdecisions.org.uk/advance_statements
- Martin G & Younger D. (2000) Anti oppressive practice: a route to the empowerment of people with dementia through communication and choice. *Journal of Psychiatric & Mental Health Nursing*, 7, 1, 59-67.
- Martyn D. (2002) *Self-Management Project Initial Report*. London: Rethink. From: www.rethink.org

Martyn D. (2003a) *Self-Management. The experiences and views of self-management of people with a diagnosis of schizophrenia*. London: Rethink. From: www.rethink.org

Martyn D. (2003b) *A bibliography of recovery, self-management and related themes*. London: Rethink. From: www.rethink.org

Mencap. (2002) *Am I making myself clear? Mencap's guidelines for accessible writing*. London: Mencap. From: www.mencap.org.uk

Mencap. (2003) *Finding your way, How to get help from social services*. London: Mencap. From: www.mencap.org.uk

Mendonça P. (2004) *Rights, independence, choice and inclusion*. London: Learning Disability Taskforce, Department of Health.

Mental Health Act Commission. (2005) *Independence, well-being and choice. Our vision for the future of social care for adults in England. Consultation response*. Nottingham: Mental Health Act Commission.

Mental Health Act Commission. (2003) *Response to the national consultation Fair for all, personal to you: choice, responsiveness and equity in the NHS and social care*. Nottingham: Mental Health Act Commission.

Mental Health Association in New York State. (2003). *Evidence-Based Practices*. USA: Mental Health Association in New York State. From: <http://www.mhanys.org/ebpdb/index.htm>

Mental Health Care. (undated) *Mental health information for friends, family and carers*. London: South London and Maudsley NHS Trust, King's College London, Institute of Psychiatry, and Rethink. From: <http://www.mentalhealthcare.org.uk/>

Mental Health Commission & Health and Disability Commissioner. (2003) *Advance directives in mental health care and treatment: information for mental health service users*. New Zealand: Mental Health Commission & Health and Disability Commissioner. From: http://www.mhc.govt.nz/publications/2003/MentalHealth_HDC_Broch.pdf

Mental Health Commission. (2004) *Oranga Ngākau: getting the most out of mental health services: a recovery resource for service users*. New Zealand: Mental Health Commission. From: http://www.mhc.govt.nz/publications/2004/Oranga_Ngakau.pdf

Mental Health Foundation. (2002) *Meeting the mental health needs of young people with learning disabilities*. London: Mental Health Foundation, Updates, 3, 20.

Mental Health Foundation. (2005) *Choosing Mental Health. A policy agenda for mental and public health*. London: Mental Health Foundation.

Mental Health Task Group. (2003) *Building on the Best. Choice, responsiveness and equity in the NHS. Top proposals on mental health.* London: Department of Health.

Mezey M, Mitty E, Bottrell M *et al.* (2000) Advance directives: older adults with dementia. *Clinics in Geriatric Medicine*, 16, 2, 255-68.

Mind. (2005) *Legal Briefing: Advance directives.* London: Mind. From: www.minmd.org.uk

Mir G & Nocon A. (2002) Partnerships, advocacy and independence: Service principles and the empowerment of minority ethnic people. *Journal of Learning Disabilities*, 6, 2, 153-162.

Monahan J, Swartz M & Bonnie R. (2003) Mandated community treatment in the community for people with mental disorders. *Mental Health Law*, 22, 5, 28-38.

Moody J. (2003) Dementia and personhood: implications for advance directives. *Nursing Older People*, 15, 4, 18-21.

Moran C. (2005) *Patient's Charter.* South London and Maudsley NHS Trust, King's College London, Institute of Psychiatry, and Rethink. From: <http://www.mentalhealthcare.org.uk/>

Morgan H. (2000) Your choice or mine? *Mental Health & Learning Disabilities Care*, 4(2), 64-67.

Morgan H. (2002a) The Choice Initiative. *The Tizard Learning Disability Review*, 7, 2, 8-14.

Morgan H. (2002b) Communicating choices: working with people with learning disabilities and high support needs. *Living Well*, 2, 1, 13-9.

Moriarty J (2005) The future of social care, *Journal of Dementia Care*, 13, 3, 10-1. June

Mortimer J. (2005) No side effects. *Openmind*, September/October, 10-11.

National Alliance for Mental Illness. (2003) *'Ticket' slow to achieve goal of consumer choice.* USA: National Alliance for Mental Illness. From: http://www.nami.org/Content/ContentGroups/Policy/Issues_Spotlights/Ticket_Slow_to_Achieve_Goal_of_Consumer_Choice.htm

National Association of State Mental Health Program Directors. (2004) *Expert panel discusses workforce issues in the face of a recovery-based care transformation.* USA: National Association of State Mental Health Program Directors. From: http://www.nasmhpd.org/spec_e-report_fall04panel.cfm

National CAMHS Support Service. (undated) *Good Practice Library*. From: <http://www.camhs.org.uk/>

NHS Executive. (1997) *The Patient's Charter and mental health services: Implementation guidance*. London: NHSE, EL(97)1.

NHS Executive & Social Services Inspectorate. (1999) *Effective Care Co-ordination in Mental Health Services. Modernising the Care Programme Approach. A Policy Booklet*. London: NHSE and SSI.

National Institute for Clinical Excellence. (2004) *Depression. Management of depression in primary and secondary care. Clinical Guidelines 23*. London: National Institute for Clinical Excellence.

National Institute for Mental Health in England. (2003a) *Developing Choice, Responsiveness and Equity in Health and Social Care*. London: National Institute for Mental Health in England.

National Institute for Mental Health in England. (2003b) *Redesigning mental health access booking and choice service improvement guide*. London: National Institute for Mental Health in England.

National Institute for Mental Health in England. (2003c) *Cases for Change - User Involvement*. London: National Institute for Mental Health in England.

National Institute for Mental Health in England & Health and Social Care Advisory Service. (2005) *Making a real difference. Strengthening service user and carer involvement in NIMHE*. London: National Institute for Mental Health in England & Health and Social Care Advisory Service.

National Mental Health Association. (2005) *Advance Directives Toolkit*. USA: National Mental Health Association. from: <http://www.nmha.org/position/advancedirectives/index.cfm>

Ness D. (2002) Discussing treatment options and risks with medical patients who have psychiatric problems. *Archives of Internal Medicine*, 162, 18, 2037-44.

Newbigging K, with Lowe J. (2005) *Direct payments and mental health: new directions*. Brighton: Pavilion, for Joseph Rowntree Foundation.

New York State Office of Mental Health. (2004) *2005-2009 Statewide Comprehensive Plan for Mental Health Services. Appendix 4: Infusing recovery-based principles into mental health services*. USA: New York State Office of Mental Health. From: <http://www.omh.state.ny.us/omhweb/statewideplan/2005/appendix4.htm>

New Zealand Ministry of Health. (undated) *An evidence-based resource about Complementary and Alternative Medicine*. From: <http://www.cam.org.nz/>

Ng Tze Pin *et al.* (2003) Preference, need and utilization of mental health services, Singapore National Mental Health Survey. *Australian & New Zealand Journal of Psychiatry*; 37, 5, 613-619.

Nicoll T. (2004) Learning disability partnership boards: making participation real? *Journal of Integrated Care*, 12, 6, 36-42.

Nicoll T & Flood K. (2005) Self advocates leading person centred planning. *Learning Disability Practice*, 8, 1, 14-7.

O'Brien J. (2004) If person-centred planning did not exist, *Valuing People* would require its invention. *Journal of Applied Research in Intellectual Disabilities*, 17, 1, 11-15.

Olofinjana B & Taylor D. (2005) Antipsychotic drugs - information and choice: a patient survey. *Psychiatric Bulletin*, 29, 369-371.

Outside the Box Development Support. (undated) *Moving On to adult life. A resource pack written by families for families*. Glasgow: Outside the Box Development Support.

Pampallona S, Bollini P *et al.* (2002) Patient adherence in the treatment of depression. *British Journal of Psychiatry*, 180, 104-109.

Papageorgiou A, King M *et al.* (2002) Advance directives for patients compulsorily admitted to hospital with serious mental illness. Randomised controlled trial. *British Journal of Psychiatry*, 181, 513-9.

Papageorgiou A, Janmohamed A *et al.* (2004) Advance directives for patients compulsorily admitted to hospital with serious mental disorders: directive content and feedback from patients and professionals. *Journal of Mental Health*, 13, 4, 379-388.

Parsons A. (2000) Briefing. Advance directives. *Mental Health & Learning Disability Care*, 3, 10, 351.

Parsons S & Theobald N. (2004) Make dreams come true. *Mental Health Today*, 34-7. December.

Paton C & Esop R. (2005) Patients' perceptions of their involvement in decision making about antipsychotic drug choice as outlined in the NICE guidance on the use of atypical antipsychotics in schizophrenia. *Journal of Mental Health*, 14, 3, 305-310.

Paul M. (2004) Decision-making about children's mental health care: ethical challenges. *Advances in Psychiatric Treatment*, 10, 301-311.

Paulson R, Post R *et al.* (2002) Beyond components: using fidelity scales to measure and assure choice in program implementation and quality assurance. *Community Mental Health Journal*, 38, 2, 119-28.

- Perkins R & Goddard K. (2004) Reality out of the rhetoric: increasing user involvement in a Mental Health Trust. *Mental Health Review*, 9, 1, 21-24.
- Perri 6. (2003) Giving consumers of British public services more choice: What can be learned from recent history? *Journal of Social Policy*, 32, 2, 239-270.
- Perring C *et al.* (2004) *Expression of choice. The communication needs of people detained in Wales under the Mental Health Act 1983.* Nottingham: Mental Health Act Commission.
- Peto T, Srebnik D, Zick E & Russo J. (2004) Support needed to create psychiatric advance directives. *Administration Policy in Mental Health*, 31, 5, 409-19.
- Playford L. (2003) Choosing the healthy option: older people's views about treatment choices for mental health and well-being. *Journal of Mental Health Promotion*, 2, 3, 32-39.
- Poll C & Duffy S. (2005) *In Control. Frequently asked questions about In Control and self-directed support.* In Control. From: www.in-control.org.uk
- Pollock K, Grime J, Baker E & Mantala K. (2004) Meeting the information needs of psychiatric inpatients: staff and patient perspectives. *Journal of Mental Health*, 13, 4, 389-401.
- Pritlove J. (2002) Your flexible friend: finance schemes in mental health. *A Life in the Day*, 6, 2, 22-5.
- Rai-Atkins A, Jama A, Wright N, Scott V, Perring C, Craig G and Katbamna S. (2002) *Best practice in mental health; advocacy for African, Caribbean and South Asian Communities.* Bristol: Policy Press.
- Ranjith G & Hotopf M. (2004) 'Refusing treatment-please see': an analysis of capacity assessments carried out by a liaison psychiatry service. *Journal of the Royal Society of Medicine*, 97, 10, 480-482.
- Rankin J. (2005a) *A good choice for mental health: mental health in the mainstream; Working paper 3.* London: Institute for Public Policy Research.
- Rankin J. (2005b) Why shouldn't we choose? *Mental Health Today*, 32-4. June.
- Rea D. (2004) Changing practice: involving mental health service users in planning service provision. *Social Work in Health Care*, 39, 3-4, 325-42.
- Read Jim. (ed). (2001) *Something Inside so Strong. Strategies for surviving mental distress.* London: Mental Health Foundation.

Read, Jacob. (2003) *Emancipation songs: individual participation by service users in mental health care*. Occasional Paper 2. New Zealand: Mental Health Commission. From:
<http://www.mhc.govt.nz/publications/2003/EMANCIPATION%20SONGS%20-%20final%20email.doc>

Read Jim. (2005) *Coping with coming off*. London: Mind.

Rees G & Waters R. (2003) *'Lost and Locked in'. Patients' perspectives on leave under Section 37/41*. London: Strategies for Living, The Mental Health Foundation, and Community Fund.

Reeves T & Stace J. (2005) Improving patient access and choice: Assisted Bibliotherapy for mild to moderate stress/anxiety in primary care. *Journal of Psychiatric & Mental Health Nursing*, 12, 3, 341-6.

Rempusheski V & Hurley A. (2000) Advance directives and dementia. *Journal of Gerontological Nursing*, 26, 10, 27-34.

Resnick S, Armstrong M *et al.* (2004) A model of consumer-provider partnership: Vet-to-Vet. *Psychiatric Rehabilitation Journal*, 28, 2, 185-7.

Rethink. (2002) *Advance directives, statements and agreements and crisis cards. Policy statement 51*. Rethink.

Rethink. (2003) *Choice, responsiveness and equity - response to consultation*. Rethink.

Richards D. (2004) Self-help: empowering service users or aiding cash strapped mental health services? *Journal of Mental Health*; 13, 2, 17-123.

Ridley J & Jones L. (2002) *Direct what? A study of direct payments to mental health service users*. Edinburgh: Scottish Executive Central Research Unit.

Ridley J & Jones L. (2003) Direct what?: the untapped potential of direct payments to mental health service users. *Disability & Society*, 18, 5, 643-658.

Riedel-Heller S, Matschinger H & Angermeyer M. (2005) Mental disorders - who and what might help? Help-seeking and treatment preferences of the lay public. *Social Psychiatry & Psychiatric Epidemiology*. 40, 2, 167-74.

Robert G, Hardacre J *et al.* (2003) Redesigning mental health services; lessons on user involvement from the Mental Health Collaborative. *Health Expectations*, 6, 1, 60-71.

Robertson J, Emerson E, Hatton C *et al.* (2005) *The Impact of Person Centred Planning*. University of Lancaster, Institute for Health Research.

Robbins D. (2004) *Treated as people: an overview of mental health services from a social care perspective, 2002-04*. London: Department of Health.

Roe D, Lereya J & Fennig S. (2001) Comparing patients' and staff members' attitudes: does patients' competence to disagree mean they are not competent? *Journal of Nervous & Mental Disease*, 189, 5, 307-10.

Rose D, Fleischmann P, Tonkiss F, Campbell P & Wykes T. (2004) *User and carer involvement in change management in a mental health context: review of the literature*. London: National Co-ordinating Centre for NHS Service Delivery and Organisation R&D.

Rose D. (2003) Partnership, co-ordination of care and the place of user involvement. *Journal of Mental Health*, 12, 1, 59-70.

Rose S. (2002) Shifting the balance of power. *Learning Disability Practice*, 5, 7, 28.

Rosen R *et al* (2005) *Public Health Views on Choices in Health and Health Care*. London: The King's Fund.

Royal College of Psychiatrists. (2002) *Changing Minds: Mental Health. A multi-media CD-ROM about mental health*. London: Royal College of Psychiatrists. From: <http://www.rcpsych.ac.uk/info/young.htm>

Joseph Rowntree Foundation. (2001) *Creating more choice for people with learning difficulties*. York: Joseph Rowntree Foundation. August.

Joseph Rowntree Foundation. (2002) *A user-controlled Best Value Review of direct payments*. York: Joseph Rowntree Foundation. May.

Joseph Rowntree Foundation. (2004a) *Making direct payments work for older people*. York: Joseph Rowntree Foundation. February.

Joseph Rowntree Foundation. (2004b) *Developing direct payments in the north east of England*. York: Joseph Rowntree Foundation. June.

Joseph Rowntree Foundation. (2005) *Implementing direct payments in mental health*. York: Joseph Rowntree Foundation.

Rudkin A & Rowe D. (2001) Planning for life. *Learning Disability Practice*, 3, 5, 22-26.

Rush B. (2004) Mental health service user involvement in England: lessons from history. *Journal of Psychiatric & Mental Health Nursing*, 11, 3, 313-8.

Rutter D, Manley C, Weaver T *et al*. (2004) Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine*, 58, 10, 1973-1984.

Saltus-Blackwood R & Kaur-Mann K. (2005) Black and Minority Ethnic mental health service users in Wales: a snapshot of their views. *Mental Health Nursing*, 25, 5, 4-7.

Sass H. (2003) Advance directives for psychiatric patients? Balancing paternalism and autonomy. *Wien Med Wochenschr*, 153, 17-18, 380-4.

Saulnier C. (2002) Deciding Who to See: Lesbians discuss their preferences in health and mental health care providers. *Social Work*, 47, 4, 355-365.

Schutt R, Weinstein B & Penk W. (2005) Housing preferences of homeless veterans with dual diagnoses. *Psychiatric Services*, 56, 3, 350-2.

Scottish Consortium for Learning Disability. (undated) *An easy guide to direct payments in Scotland. Giving you choice and control over your social work services*. Glasgow: Scottish Consortium for Learning Disability.

Scottish Executive. (2000) *The Same as You? A review of services for people with learning disabilities*. Edinburgh: Scottish Executive.

Scottish Executive. (2005) *The New Mental Health Act. A Guide to Advance Statements*. Edinburgh: Scottish Executive.

Segal S, Hardiman E & Hodges J. (2002) Factors in decisions to seek help from self-help and co-located community mental health agencies. *American Journal of Orthopsychiatry*, 72, 2, 241-9.

Segal S & Silverman C. (2002) Determinants of client outcomes in self-help agencies. *Psychiatric Services*, 53, 3, 304-309.

Slingsby B. (2004) Decision-making models in Japanese psychiatry: transitions from passive to active patterns. *Social Science & Medicine*, 59, 1, 83-91.

Social Care Institute for Excellence. (2005) *Developing social care: the current position*. London: Social Care Institute for Excellence.

Social Exclusion Unit. (2004) *Mental Health and Social Exclusion*. London: ODPM.

Sosin M & Grossman S. (2003) The individual and beyond: a socio-rational choice model of service participation among homeless adults with substance abuse problems. *Substance Use & Misuse*, 38, 3-6, 503-49.

Spall P, McDonald C & Zetlin D. (2005) Fixing the system? The experience of service users of the quasi-market in disability services in Australia. *Health and Social Care in the Community*, 13, 1, 56-63.

Spandler H & Vick N. (2004) *Direct payments, independent living and mental health. An evaluation*. London: Health and Social Care Advisory Service.

Spandler H & Vick N. (2005) Enabling access to direct payments: an exploration of care co-ordinators decision-making practices. *Journal of Mental Health*, 14, 2, 145-55.

Srebnik D. (2004) Benefits of psychiatric advance directives: can we realize their potential? *Journal of Forensic Psychology Practice*, 4, 4, 71-81.

Srebnik D, Appelbaum P & Russo J. (2004) Assessing competence to complete psychiatric advance directives with the competence assessment tool for psychiatric advance directives. *Comprehensive Psychiatry*, 45, 4, 239-45.

Srebnik D & Brodoff L. (2003) Implementing psychiatric advance directives: service provider issues and answers. *Journal of Behavioural Health Services & Research*, 30, 3, 253-68.

Srebnik D, Russo J, Sage J, Peto T & Zick E. (2003) Interest in psychiatric advance directives among high users of crisis services and hospitalization. *Psychiatric Services*, 54, 7, 981-6.

Srebnik D, Rutherford L, Peto T *et al.* (2005) The content and clinical utility of psychiatric advance directives. *Psychiatric Services*, 56, 5, 592-8.

Stancliffe R, Abery B, Springborg H & Elkin S. (2000) Substitute decision-making and personal control: implications for self-determination. *Mental Retardation*, 38, 5, 407-21.

Stancliffe R. (2001) Living with support in the community: predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 91-98.

State Government of Victoria, Australia, Department of Human Services. (2005) From: <http://www.health.vic.gov.au/patientcharter/>

Stevens S. (2001) On being the boss. *Community Living*, 15, 2, 10-11.

Street C & Herts B. (2005) *Putting participation into practice. A guide for practitioners working in services to promote the mental health and well-being of children and young people.* London: Young Minds. From: www.youngminds.org.uk

Swales N. (2005) *Barnardos CAMHS User and Carer Participation Project. Annual Report 2004-05.* Leeds City Council, East Leeds Primary Care Trust & Barnardos. From: <http://www.ru-ok.com/>

Szasz T. (1982) The psychiatric will: a new mechanism for protecting persons against 'psychosis' and psychiatry. *American Journal of Psychology*, 37, 762-770.

Szegedy-Maszak M. (2002) Consuming passion. The mentally ill are taking charge of their own recovery. But they disagree on what that means. *US News & World Report*, 132, 19, 55-7, 3 June.

- Teasdale M & Gilbert H. (2004) *Only the Best*. London: Rethink.
- Tenney L. (2000) It has to be about choice. *Journal of Clinical Psychology*, 56, 11, 1433-45.
- Thomas P and Cahill A. (2004) Compulsion and psychiatry - the role of advance statements. *British Medical Journal*. 329, 7458,122-3.
- Timms P (ed). (2004) *Partners in Care. A checklist for carers of people with mental health problems*. London: Royal College of Psychiatrists. From: www.partnersincare.co.uk
- Timms P (ed). (2004) *Partners in Care. A checklist for people with mental health problems*. London: Royal College of Psychiatrists. From: www.partnersincare.co.uk
- Timms P (ed). (2004) *Partners in Care. A checklist for psychiatrists*. London: Royal College of Psychiatrists. From: www.partnersincare.co.uk
- Thompson S. (2003) Subversive political praxis: supporting choice, power and control for people with learning difficulties. *Disability and Society*, 18, 6, 719-736.
- Tobin R & Vick N. (2004) *A content analysis of direct payment policies in England*. London: Health and Social Care Advisory Service.
- Took M. (2001) *Choice in the treatment of severe mental illness, Policy statement 37*. London: Rethink.
- Townend M & Shackley P. (2002) Establishing and quantifying the preferences of mental health service users for day hospital care: a pilot study using conjoint analysis. *Journal of Mental Health*; 11, 1, 85-96.
- Tsemberis S, Moran L, Shinn M *et al.* (2003) Consumer preference programs for individuals who are homeless and have psychiatric disabilities: a drop-in center and a supported housing program. *American Journal of Community Psychology*; 32, 3/4, 305-317.
- Tsemberis S, Gulcur L & Nakae M. (2004) Housing First, consumer choice, and harm reduction for homeless individuals with a dual diagnosis. *American Journal of Public Health*, 94, 4, 651-6.
- Tuohimäki C, Kaltiala-Heino R, Korkeila J *et al.* (2001) Psychiatric inpatients' views on self-determination. *International Journal of Law and Psychiatry*, 24, 1, 61-69.
- Ungerson C. (2004) Whose empowerment and independence? A cross-national perspective on 'cash for care' schemes. *Ageing and Society*, 24, 2, 189-212.
- Vellinga A, Smit J H, Van Leeuwen E *et al.* (2005) Decision-making capacity of elderly patients assessed through the vignette method: imagination or reality? *Ageing and Mental Health* , 9, 1, 40-8.

- Vuckovich P K. (2003) Psychiatric advance directives. *Journal of the American Psychiatric Nurses Association*, 9, 2, 55-9.
- Waddington M. (2005) Advance Directives in South Essex Partnership NHS Trust, *The Approach*, 2, 9, 6-8. Autumn.
- Walker E & Dewar B. (2001) How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing*, 34, 3, 329-37.
- Walker G & Duffy J. (2001) Up to the job. *Learning Disability Practice*, 3, 5, 10-11.
- Wallcraft J. (2003a) *Choice, responsiveness and equity in mental health services. Report to the Mental Health Task Group on view of hard-to-reach service users.* (unpublished, personal communication)
- Wallcraft J. (2003b) *On our Own Terms.* London: Sainsbury Centre for Mental Health.
- Ward L. (2003) Research matters: Learning difficulties. *Community Care*, 31-36. April to October.
- Ward L & Townsley R. (2005) 'It's about a dialogue': working with people with learning difficulties to develop accessible information. *British Journal of Learning Disabilities*, 33, 2, 59-64.
- Ware J. (2004) Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 32, 4, 175-179.
- Wareing D & Newell C. (2002) Responsible choice: the choice between no choice. *Disability and Society*, 17, 4, 419-34.
- Warner L. (2005) Review of the literature on the CPA. Sainsbury Centre for Mental Health. From: www.scmh.org.uk
- Warren R & Bell P. (2000) An exploratory investigation into the housing preferences of consumers of mental health services, *Australian and New Zealand Journal of Mental Health Nursing*, 9, 4, 195-202.
- Watson J, Cameron L & Murphy J. (2003) Don't just make the font bigger. *Learning Disability Practice*, 6, 7, 20-3.
- Welsh Assembly. (2001) *Fulfilling the Promises. The Report of the Learning Disability Advisory Group.* Cardiff: Welsh Assembly.
- Welsh Assembly. (2004) *Learning Disability Strategy. Section 7 Guidance on service principles and service responses.* Cardiff: Welsh Assembly.

Wertheimer A. (2000) *Everyday lives, everyday choices for people with learning disabilities and high support needs*. London: Foundation for People with Learning Difficulties.

Wetherell J , Kaplan R, Kallenberg G *et al.* (2004) Mental health treatment preferences of older and younger primary care patients. *International Journal of Psychiatry in Medicine*, 34, 3, 219-33.

Wheeler P. (2003) Patients' rights. Consent to treatment for men and women with a learning disability or who are otherwise mentally incapacitated. *Learning Disability Practice*, 6, 5, 29-37.

Widdershoven G & Berghmans R. (2001a) Advance directives in psychiatric care: a narrative approach. *Journal of Medical Ethics*, 27, 2, 92-7.

Widdershoven G & Berghmans R. (2001b) Advance directives in dementia care: from instructions to instruments. *Patient Education and Counseling*, 44, 2, 179-86.

Williams J, LeFrancois B & Copperman J. (2001) *Mental Health Services that work for women: Survey Findings*. Canterbury: Tizard Centre.

Williams L & Rigby J. (2004) Advance directives in old age psychiatry. *Advances in Psychiatric Treatment*, 10, 260-266.

Williams V & Robinson C. (2001) More than one wavelength: identifying, understanding and resolving conflicts of interest between people with intellectual disabilities and their family carers. *Journal of Applied Research in Intellectual Disabilities*, 14, 1, 30-46.

Williams V, Simons K *et al.* (2003) Paying the piper and calling the tune? The relationship between parents and direct payments for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 3, 219-228.

Williamson T. (2004) User involvement - a contemporary overview. *Mental Health Review*, 9, 1, 6-12.

Wills C & Holmes-Rovner M. (2003) Preliminary validation of the Satisfaction With Decision scale with depressed primary care patients. *Health Expectations*, 6, 2, 149-159.

Witcher S *et al.* (2000) *Direct Payments: The impact on choice and control for disabled people*. Edinburgh: Scottish Office Central Research Unit.

Wood A. (2001) Home choice. *Community Care*, 36-37. 6-12 December.

Wong J , Clare I *et al.* (2000) The capacity of people with a 'mental disability' to make a health care decision. *Psychological Medicine*, 30, 2, 295-306.

Wong J , Cheung E & Chen E. (2005) Decision-making capacity of inpatients with schizophrenia in Hong Kong. *Journal of Nervous and Mental Disease*, 193, 5, 316-22.

Wyoming State Mental Health Authority. (undated) *A walk through the waiver process*. From: <http://mentalhealth.about.com/library/us/blwyoming.htm>

Yanos P , Primavera L & Knight E. (2001) Consumer-run service participation, recovery of social functioning, and the mediating role of psychological factors. *Psychiatric Services*, 52, 4, 493-500.

York A and Kingsbury S. (2005) *The 7 Helpful Habits of Effective CAMHS and The Choice and Partnership Approach - a Workbook for CAMHS*. Unpublished.

14 Appendix

14.1 Members of the Project Team

John Appleby, Chief Economist, King's Fund
Lynette Cawthra, Information & Library Service Manager, King's Fund
Kathy Johnson, Assistant Enquiry Services Librarian, King's Fund
Simon Lawton-Smith, Senior Fellow in Policy, King's Fund
Sonya Lipczynska, User Education Librarian, Institute of Psychiatry
Jeevi Mariathan, Senior Researcher, Sainsbury Centre for Mental Health
Chiara Samele, Head of Research, Sainsbury Centre for Mental Health
Lesley Warner, Senior Researcher, Sainsbury Centre for Mental Health

14.2 International Experts

John Allen, New York State Office of Mental Health, USA
Judi Clements, Mental Health Foundation of New Zealand
Penny Marrett, Canadian Mental Health Association
Steve Morris, Mental Health Council of Australia

14.3 UK Experts

A wide range of key organisations and individuals were invited to contribute to this work. The following people provided valuable input through participation in the expert panel seminar and/or by making comments on the draft report.

Members of the expert panel

David Crepaz-Keay, Mental Health Foundation
Chris George, Loud and Clear
Michele Hampson, Royal College of Psychiatrists
Caroline Hawkings, Turning Point
Mary Nettle, Service User Consultant
Vicky Nicholls, Service User Consultant
Nicola Vick, Health and Social Care Advisory Service

Other contributors

Roger Banks, Faculty of the Psychiatry of Learning Disability, Royal College of Psychiatrists
Sue Brown, SENSE
Jennifer Dixon, King's Fund
Simon Duffy, Director, *In Control*
Nicola Gardner, South East London Strategic Health Authority
Jennifer Rankin, Institute for Public Policy Research
Clive Stevenson, London Development Centre for Mental Health
Jan Wallcraft, NIMHE Fellow for Experts by Experience
Kerry Williams, Rethink
Toby Williamson, Mental Health Foundation