



The Sainsbury Centre

for Mental Health

**BRIEFING 3 I**

An introduction to a topic of current importance or controversy, giving clear and independent comment and analysis of the issues that lie behind it.

Care Services Improvement Partnership **CSIP**

## Our Choices in Mental Health

Improving choice for people who use mental health services and their carers

# BRIEFING 3 I

**T**he Sainsbury Centre for Mental Health (SCMH) is funded by the Gatsby Charitable Foundation to improve quality of life for people in the UK with severe mental health problems. SCMH works to influence policy and improve practice in public services through research, analysis and development.

Its work currently focuses on tackling unemployment among people with mental health conditions and on improving the mental health of those who are imprisoned in the UK. It is affiliated to the Institute of Psychiatry at King's College, London.

## Choice in Mental Health Care

### Introduction

The Department of Health commissioned the Sainsbury Centre for Mental Health (SCMH) and the King's Fund to undertake a review of the literature on choice and mental health in July 2005, as part of its work on the Choice Themed Review. This briefing paper summarises the findings and complements the Department of Health's *Themed Review Outcome Report* (DH, in press).

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 improve standards 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 MP "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 health care and choice that they can take great pride in and that people increasingly expect” (DH, 2004).

The Government’s vision for choice in mental health is set out in *Our Choices in Mental Health* (CSIP, 2005). Its vision for people with learning difficulties, *Valuing People*, similarly outlines the issue of choice for this group of service users (DH, 2001).

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 review demonstrates, mixed. This is perhaps not surprising. At an organisational level, commissioners will have different ideas about what range and level of services are required to meet their population’s needs from limited resources. At an individual level, practitioners will have their own professional view about the care and treatment they offer. Service users’ experiences thus 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”.

Introducing choice in mental health and learning difficulty services raises many questions:

- ❖ Does choice create confusion or 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?

## The review

The review looked at the English language literature on choice in mental health and learning difficulties over the past five years, relating to adults, to children and adolescents, and to older people. An electronic literature search was undertaken by librarians at the King’s Fund and Institute of Psychiatry. This was complemented by hand searches of journals and websites. Altogether 392 publications were reviewed.

We also undertook a consultation exercise of focus groups, interviews, and email communication with service users, carers, and practitioners. Altogether 53 people contributed in this way.

An expert seminar discussed the preliminary findings of the review. Delegates included mental health service user and carer representatives, practitioners and other key experts.

Finally, we examined how choice is reflected in national policy and guidance in Australia, New Zealand, the United States of America (in particular New York) and Canada.

The full report (Warner *et al.*, 2006) includes examples of good practice and information on the use of methods, tools and media in relation to empowerment and choice.

## Key publications

Some key publications helped to shape our thinking on the issue of choice for the various groups of service users. Rankin’s *A good choice for mental health* (2005) comprehensively addressed the issue of choice for mental health service users, as did the Department of Health’s Mental Health Task Group report (MHTG, 2003). In relation to people with learning difficulties, key publications have come from Values into Action’s work on choice and control, including *Who’s in control?* (Edge, 2001), and *Making decisions* (Beamer & Brookes, 2001), and from the *Choice Initiative* (Morgan, 2002). *Best Practice in Mental Health: advocacy for African, Caribbean and South Asian Communities* (Rai-Atkins *et al.*, 2002) addressed the issues of advocacy, self help and empowerment for service users from Black and minority ethnic groups.

## Key themes

Six key themes emerged from the review:

- ❖ 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;
- ❖ The use of direct payments.

## The nature of choice and empowerment

Mental health service users’ ability to make choices may be constrained by their own lack of knowledge, information or capacity; by others’ shortcomings

(lack of appropriate and available services, staff unreceptive to the principle of user choice and restrictive referral processes); and by legal constraints imposed on those who are subject to compulsion under the Mental Health Act 1983.

Among the core principles for promoting choice is 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 their lives. Many service users we consulted, especially young people and those from Black and minority ethnic groups, were unclear about the meaning of choice, and its relevance to them. They wanted more information on what was available, as did carers.

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.

To ensure choice becomes a reality for all client groups, issues of inequality, which affect some groups such as people from Black and minority ethnic communities, and those with learning and communication difficulties, must be addressed. Providing specialist advocacy services, linguistically diverse and culturally appropriate services, and using effective methods of communication, are key.

The bottom line is that achieving service user empowerment and involvement requires adequate financial resources along with a positive commitment from professional groups. To enable service user empowerment, mental health professionals must be prepared to work in more collaborative ways and 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: a model which puts service user empowerment, and user-defined outcomes, at its heart. When medication is the preferred option, service users want full information on its effects and side effects. They want to be able to choose what medication they get and to be given support when they choose to stop taking it. The service users we consulted also wanted to choose the professionals that they saw.

### Box 1: Examples of good practice

#### *People with mental health problems*

Self-management programmes are valued by many service users, including:

- ❖ The Strategies for Living Programme at the Mental Health Foundation; (See [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk))
- ❖ Rethink's Self Management Project; (See [www.rethink.org.uk](http://www.rethink.org.uk))
- ❖ The DH *Expert Patient Programme* includes examples involving service users with mental health problems (Kennedy *et al.*, 2004).

Information on helping service users to make informed choices about medication is provided by Mind and Rethink.

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 (NIMHE, 2003).

#### *People with learning difficulties*

Through the national *In Control* programme, a model of self-directed care for people with learning difficulties is being piloted in some local authorities. (See [www.in-control.org.uk](http://www.in-control.org.uk))

The Foundation for People with Learning Disabilities' Choice Initiative has funded projects to enable people with learning difficulties to make life choices. (See [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)).

Easy Info has a website about making information easier to understand for people with learning difficulties. (See [www.easyinfo.org.uk](http://www.easyinfo.org.uk))

Values into Action provides 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. (See [www.viauk.org/](http://www.viauk.org/))

#### *Young people*

The National CAMHS Support Service website includes a directory of good practice examples, some of which relate to choice. (See [www.camhs.org.uk/good\\_practice\\_see\\_all.asp](http://www.camhs.org.uk/good_practice_see_all.asp))

*Changing Minds: Mental Health*, a CD-ROM designed for 13-17 year olds by the Royal College of Psychiatrists, includes resources and references for further information and help on mental health for young people. (See [www.rcpsych.ac.uk/campaigns/partnersincare.aspx](http://www.rcpsych.ac.uk/campaigns/partnersincare.aspx))

Unsurprisingly, service users in all client groups need information and support to help them to make informed choices, and the carers of children and young people, people with learning difficulties and older people with dementia all need information and support to make decisions on the service user's behalf.

Some key points about good practice in communication in a variety of written and other media apply generally to all service user groups, and particularly to those for whom communication is difficult. Communicating clear and accessible information to all groups of service users is crucial to facilitating choice. Techniques such as writing in plain English, and using appropriate pictures and symbols, can help. Translation and interpreting services may be needed, and there are specific ways of communicating with people who have little or no speech, or who cannot hear.

### Choice in care planning

The Care Programme Approach (CPA) and Person Centred Planning (PCP) respectively provide the frameworks for planning, delivering, monitoring and reviewing the care of people with mental health problems and those with 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 but that currently many service users and carers are not meaningfully involved. Many of those that we consulted reported negative experiences of the CPA.

#### Box 2: Examples of good practice

##### *People with mental health problems*

- ❖ Royal College of Psychiatrists' Partners in Care leaflets and checklists are designed to help service users, psychiatrists and carers with the care planning process. (See [www.rcpsych.ac.uk/campaigns/partnersincare.aspx](http://www.rcpsych.ac.uk/campaigns/partnersincare.aspx))

##### *People with learning difficulties*

- ❖ Valuing People's website has easily accessible information on PCP. (See [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)).

### 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. More work needs to be done to assess the impact of service user involvement in service planning and delivery.

The literature suggests that organisational culture and professional opposition often prevent service users from becoming fully involved in the planning, delivery 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 communities, older and younger people, and people with a diagnosis of personality disorder. The service users we consulted felt that voluntary services involved them in service planning much more than did statutory services.

#### Box 3: Examples of good practice

##### *People with mental health problems*

- ❖ Mersey Care NHS Trust has a service user and a 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.
- ❖ In Derbyshire Mental Health Services NHS Trust, service users are routinely included on staff recruitment interview panels.

##### *People with learning difficulties*

- ❖ Wiltshire and Swindon User Network (WSUN), a user-led organisation, has empowered service users to make a contribution to local policy and service developments (Evans *et al.*, 2002).

##### *Young people*

- ❖ Young Minds has produced a guide for practitioners on ensuring participation by young service users with mental health problems in planning the sort of services they would prefer to use. (See [www.youngminds.org.uk](http://www.youngminds.org.uk))

## Advance directives and advance statements

An advance directive is a way of making a person's views known if he or she should become mentally incapable of giving consent to treatment, or making informed choices about treatment, in the future. It is intended to be 'a binding refusal of treatment', for example to refuse medication or ECT, and can also allow individuals to 'opt in' to particular treatments. 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.

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, but is not legally binding.

The literature reflects that mental health service users are keen to use advance directives and advance statements to make their wishes known, and that they can also be used by people with dementia. However, while more common in the USA, they are only slowly being adopted in the UK. Some psychiatrists are unconvinced about their value, and others are reluctant to respect their validity. The evidence about whether advance directives contribute to preventing emergency and compulsory admissions to hospital is so far inconclusive. Service users we consulted said they lacked enough information to make a choice about them.

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 (see Box 4).

## 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 the recipients' quality of life. Recipients can use the payments for a wide range of services, and may choose to buy personal support and respite care or to pursue 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

### Box 4: Examples of good practice

#### *Advance directives and statements*

Derbyshire Mental Health Services NHS Trust has produced guidelines for service users on how to make advance directives to state how they would like to be treated on future occasions (Derbyshire MHST, 2004).

Mersey Care NHS Trust has introduced advance statements for its mental health service users, including their preferences about medication and a range of practical issues.

Several voluntary organisations have produced clear factsheets for service users about advance directives and statements, including:

- ❖ Age Concern (See [www.ageconcern.org.uk](http://www.ageconcern.org.uk))
- ❖ Alzheimer's Society (See [www.alzheimers.org.uk](http://www.alzheimers.org.uk))
- ❖ Mental Health Foundation (See [www.mentalhealth.org.uk/](http://www.mentalhealth.org.uk/))
- ❖ Mind (See [www.mind.org.uk](http://www.mind.org.uk))
- ❖ Rethink (See [www.rethink.org](http://www.rethink.org)).

the uptake of direct payments nationally for these groups 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 direct payments.

The literature showed that, as in many areas involving choice, support in arranging and managing direct payments is crucial for service users. People who have been supported to make use of direct payments have been very satisfied with this tool to increase their independence and exercise of choice.

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. 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.

Some of the practitioners we consulted were unsure about how direct payments could work for their clients, and some carers were also sceptical, while service users felt they did not have enough information about them.

Some commentators feel that personal recovery budgets, to include funding for both health and social care, would be particularly helpful for people with mental health problems (Rankin, 2005).

### Box 5: Examples of good practice

#### **People with mental health problems**

An evaluation of the national Direct Payment pilot schemes included a number of examples (Spandler & Vick, 2004):

- ❖ A service user who employed a personal assistant at times when she felt most vulnerable, which led to fewer incidents of self harm;
- ❖ Service users pooling their direct payments to fund two artists to run a creative arts group in a geographically isolated area.

The National Centre for Independent Living's guide to some key issues for users and survivors clearly sets out eligibility criteria, how to apply, what direct payments can be used for, and what support is available (Heslop, 2005).

#### **People with learning difficulties**

Swindon People First, a self-advocacy group for people with learning difficulties, ran a direct payment support scheme, successfully overcoming a number of barriers to access (Gramlich *et al.*, 2002).

Easily accessible information on direct payments is available on the Valuing People website. (See [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk))

#### **Older people**

Older people's use of direct payments has resulted in improved quality of life, motivation and happiness. In one area, older Somali people purchased culturally-relevant services by employing personal assistants from a similar background, where such staff were not available through social services (JRF, 2004).

### An international perspective

In a selective overview of 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 universal, and it is hard to locate any free-standing documents specifically addressing patient choice in mental health. However, choice issues are often 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 should have access to 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, while there is broad agreement that service users should have more, and better informed, choice, in practice this is not commonly available. This may arise from health professionals' reluctance to offer choices, or through 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.

In Australia, policies such as the current National Mental Health Plan do not address the question of choice directly (Australian Government, 2003). Although consumer and carer participation is built into national strategies, the accepted reality is that it is often lacking in practice through either a lack of will or service shortages.

New Zealand's National Mental Health Plan (New Zealand Ministry of Health, 1997) states the principle of "encouraging programmes and services that enable individuals, families and communities to increase control over, and improve, their mental health and wellbeing", and there are specific references to enhancing choices for the minority Maori population.

In the USA, choice is clearly seen by government as a driver in the market to improved quality of services. 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.

The Public Health Agency of Canada, on behalf of the federal government, has published a number of documents on mental health that touch on choice. For example, a recent 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 health problems is to ensure that they have power, choice, and control over their lives and mental health.

### Box 6: Example of good practice

The New York Office of Mental Health's White Paper on recovery-based principles is largely based on a consumer perspective (NYOMH, 2004).

This paper lists 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". It 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 wellbeing, community connections and social supports are essential considerations."

## 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 both the will and the resources are made available to replicate this good practice more widely. Choice clearly has a central role to play in improving the daily experience of people with mental health problems and supporting them on the road to recovery.

Mental health has often been referred to as a '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 to 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.

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