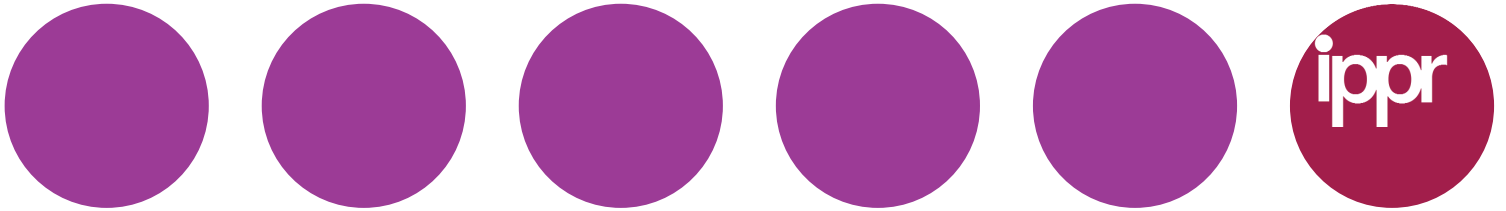


# Mental Health in the Mainstream



## A good choice for mental health

**JENNIFER RANKIN**

WORKING PAPER **THREE**

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# A Good Choice for Mental Health

Mental Health in the Mainstream  
Working Paper Three

Jennifer Rankin



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# Mental Health in the Mainstream

*What would it take to move towards a society that fully supports the rights and inclusion of people with mental health problems and knows the value of good mental health?*

Mental health is at a crossroads. On one side mental health policy is changing in response to a new agenda of human rights, anti discrimination and social inclusion; on the other it remains shaped by concerns over public order and risk management. Within specialist services, there are tensions between therapy and management and between greater user choice and service control. In society at large, there are emerging concerns about the state of public mental health and wellbeing, which is evident in the growing concern about rising use of anti-depressants. Amidst these different trends, there is no clear direction about the future of mental health.

ippr are working with Rethink on a new project that will set out a future vision for mental health policy. The main output will be an ippr report, due to be published in 2005. This report will be rooted in the experience of service users and will draw on original qualitative research. The aim is to influence future developments in mental health policy, drawing lessons from policy experiences since 1990.

In the run up to this publication, ippr will publish three short working papers, with the aim of discussing some selected issues ahead of the publication of the main report in 2005. We hope they will help engage a wide range of people in the debate. Each working paper will be a short introduction to a few key issues rather than an exhaustive study of the topic. As such, the working papers will focus on particular examples to illustrate the different themes that are shaping mental health policy.

- Working paper 1, November 2004: **Developments and trends in mental health policy**
- Working paper 2, February 2005: **Mental health and social inclusion**
- Working paper 3, March 2005: **A good choice for mental health**

In order to set priorities for the papers, ippr has worked in consultation with an external steering group. We would like to thank all the members of the steering group for their ongoing involvement in the project: Janey Antoniou, Paul Corry, Paul Farmer, Alison Faulkner, Martin Knapp, Vanessa Pinfold, Dennis Preece, Cliff Prior. The author is grateful to everyone who commented on a draft of this paper: Janey Antoniou, Paul Corry, Paul Farmer, Cliff Prior, Peter Robinson and Deborah Roche.

The project as a whole has benefited from very useful discussions with a number of people. The author would like to thank Peter Beresford at Brunel University, Dr Matthew Broome at the Institute of Psychiatry, Gary Butcher at Rethink, Sophie Corlett at Mind, Chris Fitch at the Royal College of Psychiatrists Research Unit, Carole Furnivall at The First Step Trust, Angela Greatley at the Sainsbury Centre for Mental Health, Rowan Livingstone at Social Link, David Morris at NIMHE, Rachel Perkins at South West London and St Georges Mental Health NHS Trust and Liz Sayce at the Disability Rights Commission. I would also like to thank John Schwartz and Nicholas Thorner for their valuable help in producing the three working papers. It goes without saying that any errors are the author's responsibility alone.

## Scope of the project

Mental health problems are more common than asthma. Up to one in six people experience mental health problems over the course of their lifetime, while 630,000 people have severe mental health problems at any one time, ranging from schizophrenia to deep depression. Beyond this, mental health has a far wider impact on families: there are over 1.5 million carers supporting people with mental health problems (including dementia).



As in other areas of people's lives, mental health is complicated. Mental health problems encompass a broad spectrum of experiences that affect people across the life cycle. People do not experience mental health problems in isolation; in particular, severe mental illness is frequently linked to poverty, discrimination and other complex needs. Health and social care services are demarcated by labels that mask the imprecision of people's lived experiences.

Mental Health in the Mainstream aims to reflect the diversity of people's experiences. However, the project does focus on adults with severe mental health problems, although this will be situated within mental health more broadly. It is an opportunity to explore the distinction between 'severe' and 'common' mental illness and examine the concept of public mental health. The project is primarily focused on England, but will draw on examples from the devolved nations and may be of interest beyond England.

## About the author

**Jennifer Rankin** is a researcher in health and social care policy at the ippr. Her publications include *Meeting Complex Needs: The Future of Social Care* and *Who Cares? Building the Social Care Workforce*, she has also written for the December 2004 issue of ippr's journal *New Economy*.

# Introduction<sup>1</sup>

*I believe in taking responsibility for my own life . . . I just believe in myself, myself is what gets me through things.*

(Person with mental health problems, Faulkner 2000)

*“Trust me, I’m a patient” should be the guiding principle of [the] new agenda.*

(Reid 2003a)

In July 2003 the Secretary of State for Health promised that the choice agenda would effectively turn the traditional, doctor-centred health service inside out. To date, choice has been an essential ingredient in the rhetoric around the reform of public services. It is a concept that has never been far from controversy. Choice has been presented both as the motor of public service modernisation and as an assault on the public sphere. Yet, these ideological disputes may have obscured the fact that choice actually means many different things in practice. In reality, choice varies according to who is choosing, what choices are on offer, and the extent to which the policy framework supports people in making choices.

Choice means the power to make decisions. It goes beyond ‘voice’ mechanisms, such as surveys and consultations. It is more specific than ‘personalisation’ and the amorphous concept of ‘modernisation’, although it is undoubtedly part of both these agendas. In their manifesto for the General Election of 2001 the Labour Party promised to give patients more choice in the health service (Labour Party 2001). Although at that time, choice was more aspiration than policy, it has since been spelled out as meaning choice of provider in elective surgery, as well as greater convenience for patients.

In mental health, the choice agenda has had a different evolution to the development of choice in the rest of the NHS. Arguably, it has been shaped by mental health’s unique history. People with mental health problems have been stigmatised, subject to poor practice or not taken seriously (Prior 2003). The underlying assumption of past mental health services was that patients were unable to make choices. Also unique to mental health are the coercive aspects of the service. As such, choice poses a significant challenge to established ways of delivering services and interacting with people. In the long run, the concept of choice could have a transformative effect, both on how mental health services work, as well as how society responds to mental health problems. These are the themes this paper will explore.

This paper proceeds in three parts. Part 1 provides an overview of choice in the NHS and choice in relation to mental health. It considers how the nature of choice in mental health might differ from choice elsewhere in the health service. Part 2 charts the uneven transition of mental health services from a default position of no or little choice, towards a greater role for people’s preferences. It offers an assessment of people’s current choices or lack of choices in recovery options. While this paper is focused on choice in the context of health and social care, it argues that choice cannot be isolated in these services. The principle of choice goes hand in hand with the drive towards greater social inclusion for people with mental health problems.<sup>2</sup> Finally Part 3 outlines the core principles for promoting choice in mental health, as well as the conditions necessary to support choice in practice.

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<sup>1</sup> This paper was originally conceived to discuss “the future of mental health”. In order to narrow an extremely wide-ranging subject, it was decided to focus on the implications of choice for mental health. The final report of the project will put choice in the context of other future developments.

<sup>2</sup> Social Exclusion Unit (2004) provides the Government’s strategy on breaking down social exclusion for people with mental health problems.

# 1 Understanding choice

## Choice in the health service

In practical terms, choice in the NHS has been translated as greater consumer choice and more convenience for the patient. At the forefront of the government's choice policy is the goal that by December 2005, all patients will be able to choose between four or five different providers for elective care. This policy is part of 'choose and book', where patients will be able to choose appointment times at their convenience (Department of Health 2004). Since April 2004, those waiting longer than six months for elective surgery have been given the option of another hospital for faster treatment. Choice is underpinned by new financial systems, such as Payment by Results (PBR) and Practice Based Commissioning (PBC).<sup>3</sup> The government has argued that greater choice will help to tackle health inequalities, through improving access to services for poorer patients (Reid 2003b). It has also presented consumer choice as a means to empower people and secure greater equity in the health service. The Prime Minister underlined this message "choice and consumer power [are] the route to greater social justice not social division" (Blair 2003). As the choice agenda unfolds, there will be interest in how far the Government delivers on these claims.

Mental health is one of the top three priorities for the health service. Yet, despite different policy initiatives to promote greater user involvement in mental health, the choice agenda is yet to have a significant impact on people's lives or experience of services. This has prompted reassurances from government that "the choice agenda applies as much to mental health services as anywhere else" (Winterton 2004). But, arguably, there is a good deal less to show for it. In 2003 an expert taskforce appointed by the Department of Health published detailed recommendations on extending choice in mental health. Since then there have been few outcomes, and the government has been reticent about making the links between choice and mental health (Forrest 2004). At the time of writing, the opportunity to choose between four or five providers does not apply in mental health (Department of Health 2004a).<sup>4</sup> Neither is there an alternative choice for patients who have waited more than six months for treatment, e.g. for psychological therapies. This extension of choice may be hindered by the absence of waiting list targets for mental health.<sup>5</sup>

Lack of choice in treatment is somewhat paradoxical, because there has never been so much evidence on the many potential treatments and interventions that improve the symptoms of mental health problems. The National Institute for Clinical Excellence (NICE) publishes detailed clinical guidelines covering a range of treatment options. International evidence suggests that treatment choice is essential in order to maximise effectiveness of treatment (Lehman *et al.* 2004).

Whilst choice is yet to be embedded in the day-to-day practice of services, there are policy developments on the theory of choice in relation to health and social services. The interim review of the National Service Framework (NSF) highlighted choice as an area for future service development (Department of Health 2004). The National Institute for Mental Health in England (NIMHE) are currently exploring options on choice for mental health service users, and are also looking at direct payments – individual care budgets used to purchase community care. Even the highly contested and controversial draft mental health bill contains

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<sup>3</sup> Payment by Results means that NHS Trusts will receive part of their income based on a fixed cost per case, rather than on a block contract basis. Although this only applies to the acute sector, it will be extended to outpatient, community, mental health, and learning disability services. PBC means that primary care services will be assigned responsibilities for commissioning services. These systems may have a significant impact on many areas. Both PBR and PBC share the overarching aim of making services more responsive to patient preferences. For instance PBR means that money follows the patient, whilst Practice Based Commissioning aims to improve commissioning by attuning it better to local needs.

<sup>4</sup> Specifically, the guidance referred to "services where other choices are more likely to improve patient experience" (Department of Health 2004).

<sup>5</sup> Most mental health services do not have waiting list targets (Layard 2005).

provisions to promote choice in in-patient settings; for example, those who are subject to compulsion after an initial assessment will have the right to an independent advocate (Department of Health 2004c). At the time of writing, the government is expected to publish detailed proposals on choice and mental health. But if these choice policies are to succeed on a transformative scale, mental health should be in the mainstream of the government's agenda on choice.

## **The nature of choice in mental health**

For many years service users have argued for more choice over the treatment options they are offered, as well as support in making choices to live ordinary lives (Barnes *et al.* 1999). In mental health, choice has different associations and will operate differently to choice in elective care. Choice in a consumerist sense, the opportunity to choose different providers has a less central role. Discussions with service user groups indicate people are more concerned over access to services and choice of key worker, rather than 'consumer choices' (Barnes *et al.* 1999). Some providers have cast doubt on whether choice of four or five providers is the right way of introducing choice for people with mental health problems (Forrest 2004).

Useful comparisons can be drawn with choice for people with physical disabilities. In the early 1990s the disability rights movement embraced 'consumer choice' because it made it more difficult for governments to dismiss their views. People recall how the logic of consumerism helped to secure direct payments (Barnes *et al.* 1999). Yet, there was also a sense that consumerism was an inadequate platform for other ambitions. The power of decision making was part of a much wider agenda of being treated with dignity, respect and included in society (Barnes *et al.* 1999). These findings have similar resonance for mental health. In one sense, choice is a means to an end, where the goal is a more responsive service. But, choice is also an end in itself. It is worth remembering that making choices is a manifestation of the rights and responsibilities of adulthood. For too long, this principle has been lost in mental health services.

## 2 Choice and mental health

### Background

Traditionally, the default position of mental health services has been little or no choice. Common to all kinds of mental health treatment has been a system lacking both the resource capacity and flexibility to provide a personal service that engages the individual in their own recovery. For people with severe mental health problems, the coercive aspects of services have overshadowed their experience of services (Perkins and Repper 1998).

Mental health has a unique history of containment and compulsion. In 2003–4 the Mental Health Act 1983 was used on 45,700 occasions to detain people (Department of Health 2005). This is a significant number, but relatively small in comparison to the overall number of people who have severe mental health problems at any one time (630,000). However, it has a disproportionate impact on how professionals perceive patients, how patients respond to mental health services, and how society regards mental health. Leading practitioners have argued that the knowledge that treatment can be enforced overshadows people's interactions with services (Perkins and Repper 1998). Services have also been criticised for a disproportionate concern with risk (Ryan 2002). Mental health is unique in health and social care, in that choice represents a significant challenge to the principles that underpin aspects of day-to-day practice.

Considering the experience of people in acute in-patient wards reveals a stark tension between choice and control. But beyond this group of service users, there are many more people who are less visible. There are people with long term, serious but stable mental health problems who live in the community, leading lonely, isolated lives, with few close friends or social networks. They may lack adequate options on making long term recovery, and on re-joining the labour market (Corry *et al.* 2004).

Beyond this group, there is an even larger number with relatively common mental health problems who find few options for treatment. To some extent, this is a reflection of the fact that many mental health problems go untreated. A longitudinal survey by the Office for National Statistics (ONS) shows that just under a quarter (24 per cent) of people assessed as having a neurotic disorder were receiving treatment of some kind (ONS 2000).

There is a growing knowledge and understanding on how to treat mental health problems. However, international evidence suggests that the way resources are allocated to services is not consistently linked to what treatments are shown to work in practice. Choice would help to maximise treatment response.

*[a] wide array of effective treatments should be available within a community, because even when treatments are equally effective on average, many of them are not equally effective for significant subgroups.*

(Lehan *et al.* 2004).

Yet, in practice, the opportunity to make choices about treatment remains limited. In one survey, more than 54 per cent of respondents commented that they didn't have a choice of treatment options (Mind 2002).

### Choice in Primary Care

Over 90 per cent of all those with mental health problems are seen in primary care. In theory, everyone has had a choice of GP since 1948, but this in itself has proved no guarantee of personally responsive services. GPs may not be the ideal gateway into services. Relatively few GPs have a special interest in mental health. In one study three quarters of GPs

considered they had either more interest or much more interest in general medicine than psychiatry (Boardman 2004).

People from black and minority ethnic (BME) communities are more likely to have an unsatisfactory response from primary care. For example, black people are more likely to have depression undiagnosed (and schizophrenia over-diagnosed) (Keating *et al.* 2002). Some people with mental health problems are struck off their GP's list and can find it difficult to re-register. People who have stayed in a psychiatric hospital are especially likely to experience this problem (Mind 2002).

## Talking Treatments

Access to psychological therapies frequently tops the list of priorities of those with mental health problems (Barnes *et al.* 1999, Wallcraft 2003, Forrest 2004). NICE suggest psychological treatment for mild to moderate depression and psychological treatment in combination with anti-depressants for severe depression (NICE 2004). Yet there is a gap between the demand for and provision of research on the effectiveness of various talking treatments. And, unlike acute care, there is no target on waiting lists for psychological treatments, and hence little public scrutiny of long waiting times. While the average waiting time is six to nine months, periods of two years have been reported (Forrest 2004, Paxton 2004). Pathways to talking treatments are even harder to access for some groups. Black people with mental health problems are less likely to be offered talking cures, and more likely to be given medication and coercive treatments (Keating *et al.* 2002).

People also have varying experiences with talking therapists and key workers. Whilst some experience positive therapeutic relationships, others feel alienated by less collaborative treatments:

*Yeah, really good [on their relationship with a Community Practice Nurse]. You know I couldn't have asked for better . . . the practicalities of making sure I have enough medicine to take, to helping me come to terms with my grandfather's death. You know, it's the whole range, you know from practical to emotional.* (Faulkner 2000)

*I just feel people don't [give explanations] especially the psychologists, they don't really explain the point of it and then they get annoyed if you ask them and they say they have – and I did not think they had.* (Faulkner 2000)

Mental health services are in a state of transition and have begun to address this gap in demand. In recent years the number of psychiatrists and clinical psychologists in the NHS has increased. Between 1999 to 2004 psychiatry consultants (full time equivalents) increased from around 2,524 to over 3,155, whilst the number of clinical psychologists increased from 3,763 to 5,331 (Department of Health 2004b). From 2001/2 to 2003/4 there was a real terms increase in spending on psychological therapies of 13 per cent (Department of Health 2004b). The Department of Health has acknowledged that there is a gap in psychological therapies for some components of care and also for some groups, including older people, people with learning disabilities and people from BME communities. The future goal is that psychological therapies should no longer be regarded as "optional" (DH 2004d).

Critics may argue that progress has been patchy. The uneven progress shows up in surveys of service users: according to one survey conducted in 2003, access to psychological therapies was rated as one of the top improvements and one of the most difficult services to access (Rethink 2003).

## Medication

Concern over the lack of psychological therapies has been played out against a backdrop of growing anxiety over the role and prevalence of pharmacological treatments. In particular,

public concern has the striking growth in the use of anti-depressants, particularly SSRIs (Selective Serotonin Reuptake Inhibitors) such as Prozac and Seroxat. From 1991–2001 the number of prescription items for all anti-depressants more than doubled in the UK (www.ppa.org.uk). This has been accompanied by a shift in prescribing trends towards SSRIs: SSRI prescriptions increased from 8.2 million to more than 19 million between 1999 to 2003 (MHRA 2003).

Of course many people do find medication helpful. In particular, SSRIs have fewer side effects than the older generation of anti-depressants, although they do cause withdrawal symptoms for some people (Royal College 2005).<sup>6</sup> The problem is that they appear to be the default option for time pressed GPs. In a survey by Norwich Union Healthcare of 250 GPs, eight out of ten admitted that they were over prescribing anti-depressants and three quarters said they were handing out more of the drugs than they did five years ago (Norwich Union Healthcare 2004). Another national survey showed that 98 per cent of respondents visiting a GP for mental health problems walked out the door with a prescription for medication, even though less than one in five planned to ask for it (Mind 2002). Concerns have been raised that GPs don't offer alternative treatments, such as talking treatments (Demopoulos 2004).

A related issue is that too few patients are given the knowledge to make an informed decision about their medication. Many patients receive fairly superficial guidance, with limited information about side effects or alternatives (Mind 2002). Also, doctors may prescribe without discussing potential side effects that impinge on people's lives. One young woman diagnosed with a severe mental illness recalls the experience of *"being zonked out on high doses of medication which produced severe side effects"*. To cope with the side effects she kept stopping the medication and becoming ill again. When given a choice of medication, she opted for something with the side effects least distressing to her (ABPI/ LTMCA 2001). However, too few have this level of ownership over their medical treatment or are offered alternatives.

People's experiences of medication reflect the continuing dominance of the medical model. Medication, tested through the scientific gold standard of the randomised controlled trials (RCTs) has a high status. Yet RCTs measure the effectiveness of a product, rather than whether the drug makes people feel better (ABPI/LMCA 2001). Across all types of medicine only 50 per cent of patients comply with instructions on medication, and this doesn't vary with condition, age or risk of death (Bloom 2001). The reason for non-compliance is frequently negative side effects, so from a patient's perspective, not taking medicines is often a rational act (Perkins and Repper 1998). A purely bio-medical approach is as ineffective for mental health, as it is for other health problems.

## Choice in in-patient wards

On occasion, a person's capacity will limit their ability to make choices about treatment. In the past, restrictions under the Mental Health Act have been inappropriately extended, to erode people's rights and personal freedom in very basic things (Prior 2003). People have been denied very basic choices, about eating, drinking and daily routine, much less on treatment.

In recent years, there have been some attempts to redress the balance through advance directives or crisis plans. Advance directives allow people to make choices in anticipation of times when their capacity may be diminished. They are a formal (but not legally binding) record of the service user's wishes. The National Institute for Clinical Excellence (NICE) recommends their use where possible. The potential benefits include empowerment of the service user, better communication, tolerance for people with mental health problems, and a

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<sup>6</sup> The Expert Working Group of the Committee on Safety of Medicines (CSM) concluded "that the balance of risks and benefits of all SSRIs in adults remains positive. However prescribers and patients should be more aware of the side effect profiles of these medicines and the need for monitoring of patients being treated for depressive illness or anxiety disorders. CSM has previously advised that most SSRIs should not be used in the treatment of depressive illnesses in children and adolescents" (MHRA 2004).

reduction in hospital services and judicial proceedings (Papageorgious *et al.* 2004). In one RCT, use of crisis plans did significantly reduce compulsory admissions under the Mental Health Act (Henderson *et al.* 2004). These plans are more likely to succeed when professionals are fully engaged in the process (Henderson *et al.* 2004, Papageorgious *et al.* 2004).

## Non-medical treatments

Many people want the choice of non-medical treatment options, such as complementary and alternative medicine, books or sport on prescription, access to local support services or community groups. In addition to a greater choice of GP people have reported they would like greater choice of primary care worker. In discussions with 'hard to reach' service users, people reported they wanted to see GPs who take a holistic approach, who are sympathetic and knowledgeable about complementary therapies and not just medication (Wallcraft 2003).

One vehicle for delivering non medical interventions could be through direct payments. Developed in social care, direct payments have been associated with greater flexibility, personal control and higher satisfaction (Hasler 2003). In 2003–4 17,300 adults received direct payments; of these 207 had mental health problems (Department of Health 2004b). When people with mental health problems are informed about the concept, interest is high. However, there are also anxieties that being seen to manage a direct payment could undermine other sources of support (Davidson 2002). These issues are not insurmountable. Direct payments could be an important vehicle for creating a more direct relationship between individual demand and the supply of services available.

## Community services and collective choices

As well as individual treatments people also want access to communal services. It is important not to pigeonhole choice as operating in an individual context. In the field of social care, there are examples where people use direct payments to purchase collective services instead of or, in addition to individual support. One example of this approach is In Control ([www.paradigm-uk.org](http://www.paradigm-uk.org)). At this leaning disability organisation, groups of people may choose to pool their individual direct payments to buy into collective activities. This could be equally applicable in mental health, where people may choose to buy into collective services, such as classes or community activities. It is already well known that people want to access services in non-stigmatising community services (SEU 2004).

Here are just two responses to questions on what choices people want in social and community facilities:

*I would like to mix more with able bodied people. I would like to be listened to. I would like to be able to lead a more normal social life and not feel stigmatised or marginalised.* (Wallcraft, 2003)

*Practical classes to help raise self esteem, assertiveness, in friendly and safe environment, non clinical stigmatised building.* (Wallcraft, 2003)

In addition to buying into collective services, there may also be a place for collective choices. There are examples of groups of service users taking control over providing services. In one London borough, a group of service users took over the running of a local community centre to provide services for all local people (Clark 2001). In the old Mapperley Hospital in Nottingham a group of service users and advocates converted part of the building into a modern resource centre for mental health (Taylor 2005). Relatively little is known about these developments, and collective choice is mostly ignored in the general literature on choice. However, this is an area the merits further consideration, especially in view of the active user movement in mental health.



## Life choices

The importance of community services serves as a reminder that choice is also about the opportunity to make life decisions on health, work and personal life. Of course, it is hardly surprising that people with mental health problems want to make their own life choices. Yet, if this sounds relatively uncontroversial, at times it may prove difficult to put into practice. People with serious mental health problems are one of the most socially excluded groups and have benefited least from the various initiatives to tackle disadvantage. Stigma and discrimination contribute to narrowing people's life choices in areas that others take for granted. Life choices can only be expanded when people are better supported to take up opportunities. Breaking down the barriers to social participation will help to bring about real choices in all areas of people's lives.

In a few instances, promoting individual life choices may bring difficult ethical dilemmas to mental health practitioners. Service providers may be reluctant to support people making what is perceived as a 'bad choice', especially if these choices expose the professional to public censure. This dilemma was highlighted by a case at South West London and St Georges Mental Health NHS Trust. The trust operates a successful supported employment scheme, which helped one service user to return to her chosen line of work as a lap dancer. This choice of occupation was criticised in both the national and local media. But as Dr Rachel Perkins told a Royal College of Nursing conference: "she [Dr Perkins] was not keen on the choice of job, but it was what she [the patient] wanted to do" (Allen 2004). After all, this choice of occupation is not denied to other adults. Ultimately, service providers have to follow the logic of choice.

However, there may be some circumstances when people should be prevented from making bad choices. The increasing attention to mental health and social exclusion raises the question whether people have the right to 'self exclude', for example to 'choose' to disengage with services, and shun any attempts towards a more structured life. There is some evidence to suggest that social exclusion can become a coping mechanism for people on the margins of society (The Living Project Steering Group 2004).

Public policy should be concerned with these kinds of choices and intervention can be justified on several criteria. It has been argued that voluntary exclusion dilutes social solidarity and creates inequality of opportunity (Le Grand 2003). Also, voluntary exclusion may not represent a real choice in itself, as the decision to 'self exclude' is informed by limited experiences and narrow horizons. As Julian Le Grand has observed

*If an individual only has two unpalatable choices (your money or your life) then if he or she chooses one of them (such as giving up money), it would be odd to judge the outcome as promoting individual welfare or even a just one, simply because it was the product of a choice.*  
(Le Grand 2003)

Such a false choice is as good as no choice at all. This does not apply only to people with mental health problems, but also to other 'hard to reach groups'. Thus, it can be argued that such choices can be restricted when they flow from limited knowledge of the foregone options, and are likely to result in harmful outcomes for the individual, collective welfare and social solidarity. Mental health problems in themselves are not a reason for denying people the right to make decisions about their own lives as adults.

Considering life choices highlights that the breadth and complexity of the choice agenda. If society reaches a stage where people have a choice in treatment, but no choice in life decisions, such as employment or education, the choice agenda could be judged to have failed. Choice is part of a larger agenda of social inclusion for people on the margins of society. Without steps towards greater social inclusion, people's life choices will be empty.

### 3 The way forward

*Practitioners should listen. They have expertise but patients know their own body. Break down the 'them and us' attitude*  
(Wallcraft 2003).

Choice is an ambitious and far-reaching agenda in an arena where risk management and unresponsiveness have often dominated society's. Choice is about breaking down the barriers between professional and individual service user – “them and us” – to recognise that both have a role to play in delivering better mental health.

Part 2 suggested that there is a gap between what services do and what people find effective for better mental health. Choice is an important way to create more direct relationships between people and providers; it promises better alignment between what people want and what services provide. Potentially, it could lead to more variety in services, and to services with greater cultural relevance. Choice also has the potential to help improve therapeutic relationships by putting service users on an equal platform with practitioners. As such, it has been argued that choice could have a transformative effect on mental health services, representing a step change of equal magnitude to the closure of the psychiatric hospitals (Perkins and Repper 1998).

There are many aspirations to promote choice, which are not yet reflected in people's day-to-day experiences. This section builds on this existing knowledge and examples of good practice to set out some guiding principles behind choice in mental health. From there it suggests two ways to improve people's choices and considers the necessary conditions that need to be in place if choice is to move from rhetoric to reality.

#### Principles

*In health and social care people have the right to choose their treatment*

- In future, services should be built around rights and choice. Like any other citizen, people with mental health problems have the right to make decisions about treatment choices and life choices. And, like any other service user, choices operate within the parameters of available resources (see below for a discussion of resource capacity).
- Choices in health and social care should be based on the mix and type of treatment. Anyone with a mental health problem should expect a complex, bespoke package of care. They should have a choice of different evidence-based treatments, including different kinds of talking therapies, different kinds of medication, sport or literature on prescription, complementary and alternative medicines, 'watchful waiting', or directions to community groups or local support groups.
- However, this does not preclude extending a choice of provider to mental health services. Giving people a choice of provider for evidence-based psychological therapy would help to shape services in accordance with people's demands.
- As in other parts of the NHS, the right to choose brings with it responsibilities, such as obligations to follow mutually agreed treatment plans and take up self-help options. In itself, trusting people to take greater responsibility would be a significant cultural change.

*Choice is an aspect of a personalised responsive service*

- Choice is an aspect of more personalised, user-centred services. Health and social care services need to take greater account of the complexity of individual lives, and people's experiences and aspirations outside the boundaries of health and social care.
- Alongside choice, services need to aspire to more personal, therapeutic relationships at every level of mental health. This could be achieved through an expansion of talking

therapies, but it could be as simple as promoting better personal relationships between service users and professionals, where people are respected and have someone to talk to.

*Choice applies across the spectrum of mental health*

- Choice has equal application across the spectrum of mental health services, covering primary care, secondary care, emergency care and in-patient settings. There are no aspects of services where promoting greater choice should be ruled out.
- For people on in-patient wards, this requires reconciliation between interventions designed to protect people and safeguarding rights and choices. Greater application of human rights principles could help to shift the balance away from a coercive approach. People still need to be able to make choices about everyday decisions: such as eating, drinking, seeing visitors, and daily activities. Choices in treatment could also be promoted through routine use of advance directives or crisis plans.

*Choice can be expressed through individual and collective decisions*

- Choices in mental health will often be individual decisions. As such, there could be a role for greater individual funding, through mechanisms such as direct payments.
- However, choices will not always be expressed as individual decisions, but may operate collectively, such as in user run community services. Mental health is characterised by a significant user movement, which could be drawn on in this area.

*Choice extends beyond health and social care*

- The principle of choice should add up to more than any single 'choice initiative' within health and social services. People want to make decisions about all aspects of their lives, including family life, education, employment, and social participation.
- The only instance where 'choices' may be restricted is in cases of "voluntary social exclusion", i.e. when people 'choose' to live on the margins of society. However, this restriction on choice is not unique for people with mental health problems and has equal application to others living in deep pockets of exclusion. Such cases require a complex response from services, but that is the subject of another paper.

## Recommendations

To put these principles into practice, two changes to the current organisation of mental health services are put forward.

### **New access points to good mental health**

The traditional model of the GP as the gatekeeper into mental health treatments and other services does not always work effectively. In future, people should be able to access mental health services through different agents, such as trained counsellors, nurse practitioners or other workers, based in community organisations. These access workers would be able to offer everything from a friendly ear to professional counselling, as well as offering an entry route to other talking treatments, local support groups, medication, sport or art on prescription. These different professionals could be based in a variety of mainstream community locations, such as Children's Centres, community centres, GPs surgeries and libraries. Where existing locations did not exist or were unfeasible, access workers could be based in new types of community organisations, such as Connected Care Centres (Rankin and Regan 2004).

### **Personal recovery budgets**

The NHS has often proved fairly unresponsive to people's demands for different kinds of services, notably talking treatments. Introducing greater individual budget holding, through direct payments or specific vouchers for talking therapies could help to remedy this. If people were given their own personal recovery budget they could choose their own treatment. This would also help correct a theoretical anomaly where people (at least, those who are eligible for community care) have choice in social care, but not in health care.

A personal recovery budget is in essence a direct payment for mental health. However, if it is to work, the current direct payments system will require some adaptation. Currently, only people who are eligible for community care can receive direct payments, a relatively small group which does not exactly correspond to people who need to access mental health services. In addition, modification of the provisions on direct payments will be required to enable their use in integrated social care and health settings (Glasby and Hasler 2004). Finally, there would also need to be consideration of how people with fluctuating conditions access direct payments. It would be important to ensure easy transitions, so people did not feel recovery was hampered by losing their personal budgets.

Greater choice brings with it many difficult issues. In particular, there is an open question as to how far people are responsible for the consequences of a poor choice, which has implications for the individual and overall level of resources available for others. One way to guard against poor choices is to ensure that people are appropriately supported in making decisions.

### **Conditions for good choices**

Choice is empty without a range of different options to choose from (resource capacity), clear information to choose between different options, and the support of professionals.

#### *Resource capacity*

It goes without saying that if people are going to exercise choice over their treatment options, there needs to be sufficient resource capacity in services. At the present, various talking cures are underprovided by the NHS. Richard Layard has advocated a goal of 5,000 more cognitive behavioural therapists over a Parliament, as well as doubling the number of training places for clinical psychologists (Layard 2005). Talking therapies could be provided by other trained professionals, such as counsellors, nurses or graduate primary care workers.

### *Commissioning*

Across health and social care, there have been common concerns about the commissioning function (Roche 2004, Rankin and Regan 2004). Choice will operate successfully in the context of a robust, user-focused commissioning process. Service users should be routinely involved in setting priorities for service development. Of course, it is important not to underestimate the challenges in making this shift. As the experience of one trailblazing NHS Trust has demonstrated, making user involvement a reality requires a major cultural shift (Perkins 2004). This needs to take place if services are to reflect the state of local need and become better attuned to people's preferences.

### *Care plans*

Choice means a shift towards more individualised, complex care packages. In turn, this requires detailed individual care plans. For people with severe mental health problems, it is already a requirement that every individual should have their own personal care plan. This aspiration is still some way off everyday practice, with high numbers unaware that such a care plan exists. This goal cannot be allowed to slip. There is also a commitment that every patient will have their own electronic record card and secure personal health organiser on the HealthSpace website (Department of Health 2003). These can be used to store information and record individual preferences for treatment.

### *Information*

People can only make choices with information. Everyone in touch with services should have access to clear, written information on different treatment options, providers and specialists. Information should be available in the public domain to help direct people to the right services. There is also a place for directories of providers, which contain details on interests and specialisms. For example, people may prefer to choose a GP with a 'special interest in mental health'. Providing this information in an accessible way could benefit anyone with a mental health problem and could help to make the first step into services less daunting. Clearly, the need for good information does not end once people are in services. There should be detailed information on different treatment options, such as medication and its side effects, non-pharmalogical options, and social prescribing etc.

### *Changing professional attitudes*

All health professional need training in offering supported choice. At a basic level this would include good practice guidelines that spell out choice and rights as core values of mental health services. It would include practical information on how professionals could promote choices: such as choosing different medications, and presenting the range of available treatment options for different mental health problems.

### *Professionals and independent advocates*

Beyond a long term culture change among health professionals, there would also be a role for specialist training in offering choice. One Strategic Health Authority estimates that they will require 50,000 people trained in offering choice at the point of referral (Carlisle 2005). There will be similar demand for people to support choice in mental health. Elsewhere ippr has advocated the development of a service navigator role (Rankin and Regan 2004). These would be trained professionals who could help people negotiate their way through services, and provide information on available choices; they would be based in a number of different community and primary care settings.

Outside the framework of services, there is a place for further development of advocacy services. As the Mental Health Taskforce recommended, independent advocacy could become an 'opt-out' service, rather than an 'opt-in' service (Prior 2003). Advocates could support people in their interactions with different professionals and also offer advice on making choices.

## Conclusion

At the start of this paper, choice was defined as the power to make decisions. The use of the word 'power' is no accident. The inevitable logic of choice is to re-direct power to citizens. This is why this paper has argued that choice could have a transformative effect on mental health services, and society's attitudes to mental health. In the past mental health services have been one of the most disempowering areas of public services, where people had few options and little control over finding better mental health. In a sense mental health is a test case for choice, as it reveals how serious the Government is about empowering people.

As such, this paper has presented a series of principles that should guide choice in mental health.

- 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.

Following these principles, this paper makes two recommendations. First, the GP should no longer be the sole gatekeeper into services; instead there should be new ways to access mental health support through different types of worker based in community organisations. Secondly, people should be entrusted with their own personal recovery budgets, adapted from the current practice of direct payments. This would require pilots to test how joint health and social care personal budgets work in practice.

In turn choice will only become a reality, if certain conditions are put in place. In particular, this paper singled out extended resource capacity, better commissioning, use of individual care plans, a change in professional attitudes, creating roles for professionals and independent advocates to support choice and good information. Resources are a key issue here; the current allocation of resources does not reflect people's preferences, and there are high levels of unmet demand for certain treatments, especially talking therapies.

Looking beyond services, policies need to reflect our intuitive understanding of making choices, choices over everyday life and future decisions. Extending these choices will depend upon the success of various strategies to tackle social exclusion. Judging on these issues, choice will be a challenging policy to make a reality.

Ultimately, the "trust me I'm a patient" approach heralds a step change in mental health policy. Choice holds out the prospect of more effective, more efficient services that are aligned to the interventions that work for individuals. Choice is also an end in itself, and could help to reinforce other agendas on rights and social inclusion.

Mental health problems affect at least one in six people in the general population, as well as a high proportion of people who experience multiple disadvantages and live on the margins of society. More choice holds out the prospect of better mental health services and ultimately better mental health. These issues are too important to be ignored.

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