Choice in the English Mental Health System:

A Policy Briefing

SANE 2008

Meeting the challenge of mental illness

Foreword

Choice - shared expectations

The promise of giving choice to patients in the care and treatment they receive has been heralded as a potential reformation in health care. Only last month in its revised guideline, the National Institute for Health and Clinical Excellence identified patient choice as one of the most influential factors in achieving effective outcomes in the treatment of schizophrenia. Choice has similarly been promoted as important in helping people with other conditions.

But what does choice mean, not only for the individual seeking treatment but to families and carers and the professionals and providers of mental health services? People may have different and conflicting perceptions, as choice is a chameleon word changing colour to its context. It is open to myriad interpretations.

In the health context, choice should be a relatively straightforward concept:

- people should be given information and guidance to be able to discuss and choose any medication they may need
- they should be made aware of the full range of drugs and treatments available
- psychological and other therapies, activities and social interactions they may find helpful should be considered part of a treatment package.

SANE has been researching the views of patients, families and providers in an attempt to shed light on the variety of meanings given to choice, and their implications. In order to make choice more than rhetoric, we believe the first step is to suggest some shared definitions, perceptions and understandings, so that expectations on all sides are more realistic and choice therefore a more effective lever for change.

Unless we move forward in this way, choice will remain a political aspiration for the vocal few, not the many thousands who would benefit from more involvement in those vital treatment decisions affecting their lives.

Marjorie Wallace,
Chief Executive,
SANE

Introduction

In recent years, choice has been central to the Government's plans for reform across all health services including mental health.

Although choice is available in some areas of healthcare, there is emerging evidence that choice in mental health continues to be an unmet need. In this briefing, SANE presents evidence[1] to illustrate some of the challenges of implementing choice in mental health and proposes solutions.

The choice agenda

Following a statement of intent and a national consultation, which showed that people wanted choice, information and a health service tailored to their individual needs, the Government made choice a key concept in The NHS Improvement Plan: Putting People at the Heart of Public Services[2] published in 2004. Choice formed a significant element in guidance on implementing the NHS Improvement Plan[3] issued in 2005 and the report of the NHS next stage review (published in June 2008) also included a particular focus on choice.

However, while there has been significant activity around creating and measuring choice in mainstream health services and plenty of reference to choice in mental health policy papers, there is currently no clear definition of choice in mental health.

In 2006, the Care Services Improvement Partnership (CSIP), published Our Choices in Mental Health[4] which described a framework for extending choice in mental health services, in terms of the types of choice (what, how, where, when and by whom, treatment should be provided), the preconditions of choice (capacity, quality and service user and carer empowerment) and the expected impact of choice (better outcomes, improved service quality and a more person-centred healthcare system).

The document reflected, but did not make explicit, a concept of choice that seemed to depart from the one used in general health care.

Executive Summary

- **Choice** is central to government policy and NHS reform yet choice in mental health is not being delivered equally to all[1]
- The definition of choice in mental health is unclear: consumer style vs. shared decision making
- **Choice** is defined differently by service users and service providers, resulting in variable expectations
- **Choice** is not equal with some types of choice being more available than others
- Service users are largely positive about the concept of choice and it can promote continuity of care
- Wide variations exist in the systematic monitoring of choice
- A central framework including **Key Performance Indicators** may help to transform the principle of choice into reality
- The **Choice** and **Medicines Toolkit** provides the foundations to support the process of shared decision making

SANE research

SANE sought to explore the concept of choice within English mental health services from the perspective of those who are using and providing them. In the spring of 2008, SANE's research department interviewed 81 people involved with mental health services including service users, carers, clinicians (both psychiatrists and GPs) and chief executives of mental health trusts[1].

Results and conclusions

Interpretation of choice

Key Points

Should choice be different for general and mental health services?

Choice is defined differently by service users and service providers

Definition of choice: consumer style vs. shared decision making

Choice is a dynamic process

Choice as a political tool

The standard definition of choice across the wider health service appears to be that it amounts to making a selection from a range of available alternatives. The **'Choose and Book'** system embodies this definition and is analogous to consumer choice. In mental health however, SANE's research has identified a wide range of definitions of choice.

A common definition of choice among both service users and providers in mental health is that the 'decision-making process' should be led by the service user. In practice this view of choice tends to manifest itself as 'shared decision making', where the goal is a consensus between service user and treatment provider following a discussion. Only rarely are people involved with mental health services (including service users themselves) comfortable with the idea that service users should make fully independent, consumer-style choices about care.

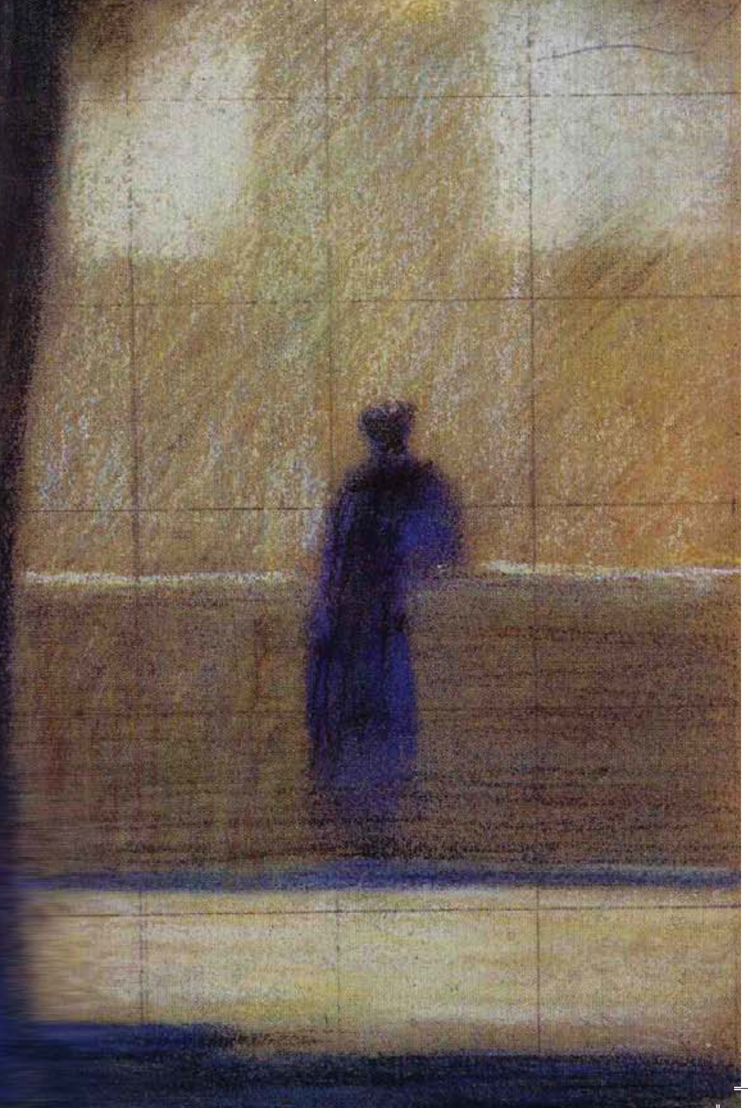
There were significant differences in how the trust executives interviewed defined choice. Some prioritised the 'standard definition' and emphasised the importance of equality between mental and general health services. Others felt that choice should be interpreted differently for mental health against the background of the Mental Health Act and the often chronic and sometimes unquantifiable nature of mental health problems.

This variation in definition was matched by significant differences between trusts with respect to how embedded the concept of choice is in policies and strategies. Choice was present in the policy frameworks of fewer than half the trusts in our research, and the trust executives that we interviewed had very different ideas about how and where choice should be constrained, suggesting a distinct need for debate in this area.

The research also highlighted the importance of interpreting choice as a dynamic process, 'tinkering' with care in an ongoing process of consultation and revision. Though likely to be more resource intensive and require more flexibility from the services, dynamic choice is viewed as the most appropriate approach because it blurs the line between success and failure, makes managing risk and conflict of ideas about best interest easier, and results in care that is more responsive to changing circumstances and personal experience.

Choice is also viewed as a political tool. Does 'choice' articulate commercialisation of health care, or an extension to the service user movement, or both? Does the choice agenda present an unrealistic image of health care? If 'choice' entails competition, who is going to make sure that it results in better services, not loss of diversity and reduced service quality?

These variations in the definition of choice are likely to result in disparity between the views of service users and providers as to the success of the choice agenda in mental health. Those following the 'standard definition' generally find the mental health service unequal to other health services with respect to choice.



Implementation of choice

Key Points

Choice is not equally available

Some types of choice are more available than others

There are variations in the systematic monitoring of choice

A framework is needed to transform the principle of choice into reality

Our research found that from the perspective of service users and other participant groups, the NHS mental health services are not currently delivering choice equally to all. While the majority want decision making to be shared, in reality many service users still experience a 'paternalistic' service, whereby choices are made by the clinician or organisation providing the care.

"Was I given a choice about it? Well yes, and no… it was never really explained."
A service user

"The issue of medication has always been decided for me by professionals and the only way I've been able to disagree and get it changed [is] if I've had a lot of side-effects… Then, sometimes reluctantly, things have been changed. But the tone tends to be at the moment that you will do as you're told."
A service user

The extent to which service users are able to participate in decisions about care can depend on how informed they are, on how assertive they or their carer are, and on the consulting style of the particular clinician they are seeing.

Deciding between different medicines and psychological interventions are areas where lack of knowledge, information and expertise forms a notable barrier to service user participation.

"Because we don't know much about it we really have to trust the GP now that they're going to make sensible decisions about how long he carries on, on it. It's difficult."
A carer

"For the most part patients will accept whatever you choose to prescribe to them; because their knowledge is limited…The less informed ask fewer questions, that's the rule."
A GP

The research indicated that some types of choice appear to be more available than others. The extent to which service users have available alternatives can depend on the type of choice they are making.

Lack of available talking therapies can mean that there is no alternative to drug treatment and even where psychological interventions are available, the range is limited and there may be long waiting lists. There may also be a lack of awareness amongst service services regarding talking therapies and other alternatives.

Choice of psychiatric consultant is also largely absent, yet many service users perceive this to be critical to their care by facilitating a therapeutic relationship. Even when there are reasonable grounds for complaint, an alternative clinician may not be available. This situation may have been exacerbated by the increased specialisation of mental health teams which may now only have one consultant attached to each team.

Our research suggested that choice for people using mental health services is currently monitored systematically only in those trusts that include choice in their policy frameworks or have clear stand alone choice policies. This may mean that the availability of choice for a service user will be dependent on their locality.

Whilst choice may be present in principle in many trusts, lack of centrally created statutory requirements for implementation and monitoring may mean that trusts prioritise other areas on which they are measured instead.

Expected impact of choice

Key Points

Expectations are variable

Service users are largely positive

Choice can promote continuity of care

Expectations regarding the impact of choice vary greatly. For example, the trust executives in our research had widely divergent views on if and how service users' choices could impact on service quality. This was particularly true of their views on the role of competition in service improvement.

On the other hand, service users' expectations regarding the psychological impact of choice are largely positive. For them, being given choice can offer recognition of their capacity for decision making, enable them to find and acknowledge their own strength to make decisions, and help them to gain a sense of control over their illness and care. However, not every service user wants to make choices about health care, and those who do, may not want to do so every time.

Choice can actually promote continuity of care, rather than disrupt it. Although some clinicians have expressed concern that service users might move between consultants given the choice, SANE's research indicates that it is more likely that service users would choose to see the same consultant even if it meant some travelling. A familiar relationship is considered likely to promote successful shared decision-making.

Current barriers to implementing choice

A central challenge to implementing choice in mental health is finding a way for clinicians to operate compatibly with it. Clinicians are a source of information and expertise and therefore have to negotiate subtle differences between being selective and biased in the information they provide. When a service user's ideas about their best interest conflicts with the clinician's opinion, the latter has to decide whether it is appropriate to attempt persuasion.

The perceived lack of available resources means that many involved in mental health view it as a crisis-led service, which only the most ill are able to access.

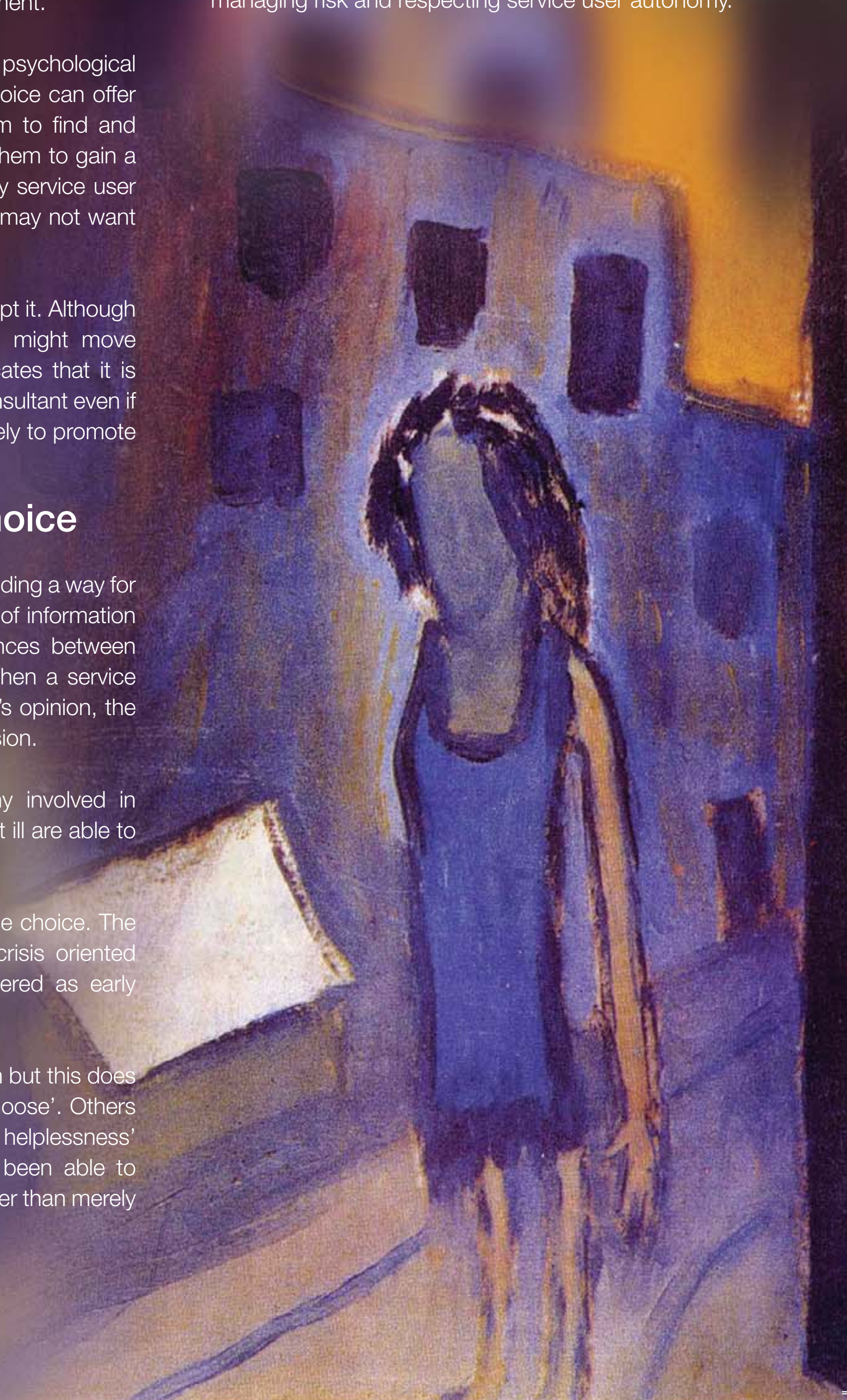
However, those who are very ill are often the least able to utilise choice. The promotion of choice requires a move away from the acute/crisis oriented model, towards one where minimally restrictive care is delivered as early as possible.

Some service users appear to accept the paternalistic approach but this does not necessarily mean that they are actively 'choosing not to choose'. Others may not be aware of the concept of choice or may have 'learned helplessness' from long-term exposure to a system where they have not been able to exercise choice previously. Choice needs to be encouraged rather than merely facilitated within the consulting room.

For clinicians and service users to achieve shared decision making, an ongoing process of consultation will be needed and a culture shift within services.

Mental health services are generally very risk averse and there may be a perception that allowing service users to make choices involves a degree of risk. Current reforms (including but not limited to choice) are shifting responsibilities for care, and this is a potential source of uncertainty and stress for staff, carers and users alike, particularly when they are faced with the possibility of 'bad decisions'.

The choice agenda highlights the balancing act between managing risk and respecting service user autonomy.



Choice in mental health:

A call to action

SANE is calling for a concerted effort to tackle the disparity in the implementation of choice in the mental health system. To achieve this, we propose the following:

1. A clear definition of choice in mental health and guidance on implementation to manage expectations, facilitate monitoring and ensure accountability.
2. Development of a choice framework which defines Key Performance Indictors to be delivered by all trusts. These KPIs should be specific and measurable and should be monitored by the Healthcare Commission as part of the annual health check process.
3. The choice framework should be developed with strong representation from service users and carers, as recommended in the NHS Next Stage Review on patients and healthcare professionals working together to provide more information and choice for the patient.
4. When medication is a treatment option, mental health providers should adopt the use of the NIHME/UKPPG Choice and Medicines Tool[5] to enable service users, clinicians and carers make an informed and inclusive decision about appropriate medication.
5. A review of the design and organisation of mental health services in order to support a dynamic, ongoing process of choosing care and shared decision making.

References:

1. Choice in the English Mental Health System, Research Department, SANE, July 2008
2. The NHS Improvement Plan: Putting People at the Heart of Public Services, Department of Health, 2004
3. The NHS Improvement Plan, Department of Health, 2005
4. Our Choices in Mental Health, Care Services Improvement Partnership, 2006
5. NIMHE/UKPPG Choice and Medicines Toolkit - http://www.choiceandmedication.org.uk/index.php

About SANE

SANE is a UK-wide mental health charity established in 1986 with three objectives:

- to raise awareness and respect for people with mental illness and their families, improve education and training, and secure better services
- to undertake research into the causes of serious mental illness through The Prince of Wales International Centre for SANE Research
- to provide information and emotional support to those experiencing mental health problems, their families and carers through SANEline and SANEmail.

The charity campaigns to combat stigma and ignorance and improve care through media activity and participation in a wide range of government, professional and service initiatives.

SANEline is the only out of hours mental health helpline open every day of the year throughout the UK. SANE's Caller Care service provides support to callers at times of crisis and ongoing need, and the discussion board on the SANE website enables people experiencing mental health problems to provide mutual support.

www.sane.org.uk

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