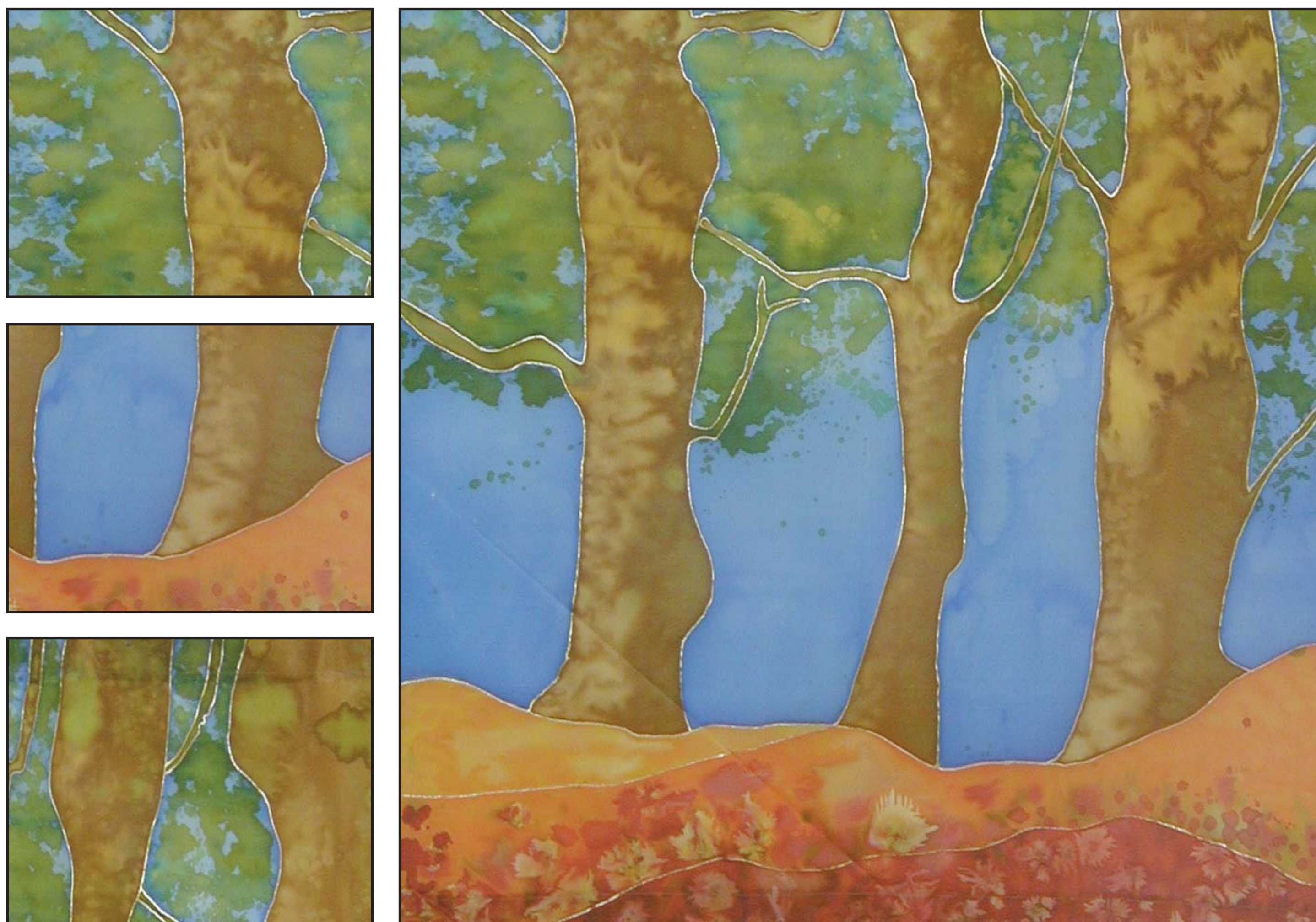
NHS

National Institute for Mental Health in England

Cases for Change

Introduction



mental health questions? **ask NIMHE**

Cases for Change

Mental health services in England are experiencing a period of unprecedented change. The pace of this change is potentially matched only by the pace at which information about both effective and less effective practice in mental health care is emerging. Over the past five years an incredible wealth of published literature has continued to remind all those engaged in developing mental health services of the reasons why fundamental change is necessary and of how services might be improved to better meet the needs of service users.

In addition to the evidence emerging from the research literature, it is important to recognise the role that publications appearing beyond the peer-reviewed journals have also had in informing the many cases for change that exist in adult mental health care today. These include publications reporting non-research based service reviews and the expert opinion of groups and organisations representing the interests of mental health service users, carers and professionals.

For those engaged daily in supporting change in local mental health services it can be difficult to feel well informed of the context of evidence and opinion within which current mental health policy has been established. With this in mind, in late 2001 the National Institute for Mental Health in England (NIMHE) commissioned a review of recent literature on adult mental health services with a view to producing an accessible summary of the emerging cases for change.

Cases for Change comprises ten booklets.

- **Introduction:** describes the background and methodology of the review and also summarises the findings and suggests areas for future research/policy development.
- **Policy Context:** describes the context of the review with an overview of recent mental health policy.

The following seven booklets each consider a different aspect of mental health service provision:

- **Primary Care**
- **Community Services**
- **Hospital Services**
- **Forensic Mental Health Services**
- **Partnership Working Across Health & Social Care**
- **User Involvement**
- **Anti-discriminatory Practice**
- **Emerging Areas of Service Provision:** reviews the literature that does not fit neatly into any of the previous topics.

The review collates evidence from over 650 documents published between January 1997 and February 2002 concerning adult mental health service delivery and/or policy in England. With the information collected synthesised into a number of key themes or issues, the review aims to describe how we got to where we are today and sets out the cases for change from the evidence base.

The articles highlighted at the beginning of each booklet as The Nature of the Evidence are those that are particularly relevant to the cases for change cited in the booklet concerned. Each document within the review has been classified using the "hierarchy of evidence" adopted in the *National Service Framework for Mental Health (NSF)* (Department of Health, 1999a):

- Type 1 evidence represents at least one good systematic review, including at least one randomised controlled trial.
- Type 2 evidence represents at least one good randomised controlled trial.
- Type 3 evidence represents at least one well-designed intervention study without randomisation.
- Type 4 evidence represents at least one well-designed observational study.
- Type 5 evidence represents expert opinion, including the opinion of services users and carers.

At the end of each of the main booklets, there are critical commentaries by service users and practitioners/managers/policy analysts from across England. These commentaries are intended to emphasise that different groups of people have different priorities and identify different cases for change. All contributors have been encouraged to be as challenging as possible and, where they disagree with interpretations, to say so.

Each booklet can be read independently or alongside one another to bring together a full picture of the development of mental health services. We hope this will be helpful in enhancing our understanding of the history as well as emphasising the need to develop future individual services within the context of an integrated system of care and support.

Cases for Change should be seen as a starting point and as a means to an end rather than an end in itself. By summarising the key issues that have emerged from the literature and by emphasising the diversity of opinion that exists within mental health services, Cases for Change may help to encourage debate about the best way forward and the way in which different view points can be balanced to achieve mutually beneficial outcomes.

Cases for Change has been written by a multi-disciplinary research team based at the University of Birmingham with the active support and encouragement of Susannah Rix at NIMHE Eastern, the guidance of the Expert Panel, and service users and practitioners who have provided written commentaries for the main sections of the review. Our thanks also to colleagues in the mental health group at the Department of Health for their editorial input to help finalise the publication.

The research team comprised:

- Jon Glasby, a qualified social worker and a lecturer at the Health Services Management Centre.
- Helen Lester, a GP, national primary care career scientist and Co-Director of the University of Birmingham's Interdisciplinary Centre for Mental Health.
- James Briscoe, a consultant psychiatrist and senior lecturer in the University of Birmingham's Department of Primary Care.
- Marion Clark, a former teacher who worked on this study as a user consultant.
- Steve Rose, Library and Information Services Manager at the Health Services Management Centre at the time of this review and now Health Care Libraries Manager, University of Oxford.
- Liz England, a clinical research fellow in the University of Birmingham's Department of Primary Care.

Four Seasons

These original artworks were designed and painted by a team at The Hollies in Ipswich, Suffolk. Working together the group generates ideas, energy and input. The community spirit engendered provides a platform that allows creativity to shine through. The group experience builds confidence and develops a sense of esteem. *"This kind of work may not cure our problems, but this is the first year I have not been admitted to hospital".*

The Hollies is a Social Enterprise developing meaningful work opportunities for people who have used mental health services. Social Enterprise can and does create real jobs. The pictures illustrate a theme of constant change and renewal in nature. They reflect the changes that can evolve through Social Enterprise and working together.

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Introduction

Background

Mental illness is as common as asthma and the costs for depression alone are as high as for coronary heart disease (Department of Health, 1998a). According to the mental health charity Mind (2000):

- One in four people seek help for mental health problems at some time in their life.
- Over 4,000 people take their own lives each year.
- More than two million prescriptions are issued every year for major tranquillisers, while minor tranquillisers account for over 19 million prescriptions.
- Over 250,000 people are admitted to psychiatric hospitals annually.

Despite this, mental health services have tended to be considered as a low priority – one of the so-called Cinderella services. As a result, anyone wishing to reform existing service provision will have a significant task ahead of them and will need to compensate for a substantial history of neglect. As the Department of Health (1998a, p.3) observes:

"Although with staff dedication and commitment, the policy of care in the community has benefited many, there have been too many failures. Failure has been caused by:

- *Inadequate care, poor management of resources and underfunding.*
- *The proper range of services not always being available to provide the care and support people need.*
- *Patients and service users not remaining in contact with services.*
- *Families who have willingly played a part in providing care being overburdened.*
- *Problems in recruiting and retaining staff.*
- *An outdated legal framework which failed to support effective treatment outside hospital."*

In response to issues such as these, there has been a noticeable increase in the rate and pace of change. Since 1997, there have been a stream of policy initiatives, consultation documents and reforms that seem set to alter significantly the way that services are provided (see the Policy booklet for an overview of key developments).

Against this background, the National Institute for Mental Health in England commissioned a review of recent literature on mental health services with a view to producing an accessible summary of the cases for change in adult mental health services that gathered together, reviewed and synthesised the literature on the evidence for reform in mental health services.

The title of this review – Cases for Change – is significant. Initially, it was to be entitled The Case for Change. However, mental health services are extremely complex and involve many different groups of people, all of whom may have very different experiences and views about what should happen. As a result this publication highlights a series of cases for change with different groups emphasising different themes and issues.

Methods

This review is based on documents published between January 1997 and February 2002 supplemented by policy guidance published during 2002 that provide evidence concerning adult mental health service delivery and/or policy in England. The review has been conducted in five main stages.

1. Evidence identification

Initially, a search strategy was devised to identify relevant material from the following databases:

- Applied Social Sciences and Abstracts (ASSIA)
- CareData Abstracts
- The Health Management Information Consortium (HMIC)
- Healthstar
- Medline
- Social Sciences Citation Index
- Turning Research Into Practice (TRIP)

The literature review was as broad as possible, including documents produced by a range of different people in a number of different formats. While reviews such as this tend to focus on papers in academic journals, material written by/for service users and practitioners was deliberately included to reflect the broad spectrum of opinion on the cases for change in adult mental health.

Throughout, search terms were based on the research team's knowledge of the mental health literature and the thesaurus terms used by the databases in question. However, additional search terms were also developed by asking local mental health practitioners, managers, policy makers and academics to suggest key phrases that may help to identify relevant material. Those who contributed to this phase of the review in February 2002 included:

- Jan Oyebode, Department of Psychology, University of Birmingham.
- Frances Badger, School of Health Sciences, University of Birmingham.
- Tina Braithwaite, SUREsearch users group, University of Birmingham.
- Max Birchwood, Director of Early Intervention Services, Birmingham.
- Di Bailey, Department of Social Policy and Social Work, University of Birmingham.
- Andre Tylee, Professor of Primary Care Mental Health, Institute of Psychiatry, London.
- Jackie Lynton, Mental Health Development Lead, Birmingham.
- Simon Foster, Chair of Carers in Partnership, West Midlands.
- Lawrence Moulin, Joint Project Manager and NSF lead, Birmingham.

Sample search terms for one of the databases (HMIC) are listed below as an illustration of the approach adopted:

Mental-health-care or mental-health-services or health-service* or primary-health-care or health-promotion or health-education or mental-health-education or service-development or hospital-care or hospital-services or community-mental-health or in-patient-care or out-patient-services or acute-services or forensic-p* or (psychiatry* in de) or (psychiatric* in de) or behaviour-therapy or psychotherapy* or psychopathology* or rehabilitation* or psychiatric-rehabilitation or rapid-response* or (respite in de) or home-care or informal-care or (prison* in de) or (outreach* in de) or clinical-psychiatry* or clinical-psychology* or drop-in* or PACT or DAPA or IRIS or (early adj intervention) or (talking adj therap*) or (psychological adj therap*) or (cognitive adj behaviour*) or (assertive adj community*) or counselling* or (crisis adj resolution) or crisis-intervention or (recovery adj based adj programm*) or care-programm* or (functional adj model*) or psychiatric-emergency* or (emergency* in de) or community-care)
and Mentally-ill* or mentally-disordered* or (mentally adj disordered) or mental-health* or schizophren* or (psychiat* in de) or psychosomatic-disorders or mental-disorders or psychosis* or (manic adj depress*) or

depression or dementia or senile-dementia or carers or psychopathic-p*

A search was also conducted of the following websites:

- Audit Commission
- Bandolier
- Cochrane Library
- Commission for Health Improvement.
- Department of Health: POINT database and 'What's New' pages.
- Health Advisory Service
- Mental Health Act Commission
- Mental Health Foundation: research and policy briefings
- Mind
- The NHS Learning Zone
- National Institute of Social Workers
- National Schizophrenia Fellowship (now Rethink)
- Primary Care Mental Health Education
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Psychiatrists
- Sainsbury Centre for Mental Health
- Social Services Inspectorate
- University of York NHS Centre for Reviews and Dissemination

This initial search was supplemented by seminal documents identified by the expert panel or from the research team's existing knowledge of the mental health literature (both before and after 1997). These articles are listed separately in the Bibliography as 'wider literature.'

2. Exclusion criteria

The breadth of the original literature search ensured the review was as comprehensive as possible. Helen Lester and Jon Glasby then narrowed the focus of the review by excluding documents that predominantly concerned the following issues/areas:

- Services for older people.
- Services for people with learning difficulties.
- Services for young people aged 14 and under.
- Sex offenders.
- People with a personality disorder.
- Substance misuse.
- Material based primarily on individual opinion.
- Inspection reports or service reviews which focus on specific geographical areas of the country.
- Therapeutic pharmacological interventions aimed at the individual.
- Serious and untoward incident reports and public enquiries into care.
- Material focusing on services outside England.
- Purely theoretical papers (unless applied in evaluating service delivery/policy interventions).
- Training and educational interventions/material (unless directly relevant to the cases for change in a particular area).
- Press releases.
- Documents that summarise material already included in the review.
- Outcome scales.
- Probation services that did not deal specifically with mental health.
- Clinical governance issues that did not deal specifically with mental health.
- Protocols and guidelines (including risk management guidelines) unless specific to changes in mental health service delivery.
- Clinical audit.
- The management of violence (unless specific to mental health service delivery).
- Postnatal mental health issues.

The first 200 documents were jointly reviewed to ensure that both researchers were applying the exclusion criteria in the same way.

As a result of this process, 653 documents were identified, all of which were successfully obtained, reviewed as part of this report and included in the complete Cases for Change bibliography. The articles highlighted at the beginning of each booklet (The Nature of the Evidence) are those that are particularly relevant to the Cases for Change cited in the booklet concerned.

3. Evidence synthesis

Identified relevant documents were synthesised using both an analytical approach based on Glaser and Strauss' (1999) method of grounded analysis and also triangulation that enabled comparison of qualitative and quantitative data from different studies (Mays et al., 2001). Grounded analysis involves immersion in the empirical data in order to identify the key themes and issues. As these themes began to emerge, they were constantly re-tested against the literature in order to ensure that they continued to provide a satisfactory explanation of the empirical data.

4. Appraisal of quality

Once a review extends beyond randomised controlled trials, the assessment of the quality of studies inevitably becomes more complex and potentially more reliant on informed research judgement. A number of classificatory schemes and assessment criteria have been devised for quantitative research, designed essentially to determine the degree to which findings are free from bias or error. The hierarchy of evidence adopted in the *NSF for Mental Health* (Department of Health, 1999a) was used to classify the Cases for Change documents:

- Type I evidence – at least one good systematic review, including at least one randomised controlled trial (that is, a review that uses systematic and explicit methods to identify, select and critically appraise all existing relevant research, and to collate data from the research that is identified to answer a clearly formulated question. As an example, a systematic review might combine the results from all completed studies to determine the overall effect of a particular treatment).
- Type II evidence – at least one good randomised controlled trial (that is, an experiment where the researcher decides which people (e.g. patients, people who live in a particular town, people who go to a particular GP practice) are given a particular intervention (e.g. a new treatment or system of care) and which get usual care (usually called a control group). This allocation to intervention or control is done on a random basis to enable an unbiased comparison of the two groups. For example, when assessing whether a new drug is better than the existing one, patients would be randomly allocated to receive either the new drug (intervention) or the drug that is usually prescribed (control). The number of patients cured in each of the groups, and any adverse effects, would be compared before deciding if the new drug should be routinely used in preference to the existing one).
- Type III evidence – at least one well designed intervention study without randomisation (that is, where the researcher intervenes to decide which subjects are given the intervention and which get usual care. This decision is however not done on a random basis, usually for practical reasons. For example, when the effect of fluoride on dental cavities was investigated, the water supplies of some towns were fluoridated and the subsequent rate of dental cavities in these towns was

compared with the rate in towns where the water was not fluoridated).

- Type IV evidence – at least one well designed observational study (that is, where the researcher does not actively intervene, but observes what is happening).
- Type V – expert opinion, including the opinion of users and carers (that is, the opinion of one or a group of people who have special knowledge or interests in a particular area. The group may be a panel of professionals with expertise in a particular area of healthcare, a group of patients who have experienced a particular condition or a group of carers).

A single hierarchy of evidence is, however, inappropriate to describe qualitative research and a number of different schemes for assessing the quality of qualitative research have been developed. This study therefore also draws on that described by Mays et al (2001) and Mays and Pope (2000) which includes a consideration of the clarity of the research question, the design, setting, sampling methods, thoroughness of data collection, rigour of data analysis and implications for policy and practice.

There has been no attempt to provide a strength of recommendation based on the categories of evidence since the potential power and impact of a study lies beyond a description of the basic design. Human testimony and single site experience can sometimes be as influential in policy terms as systematic reviews or randomised controlled trials.

5. Expert panel

The project has been overseen by an expert panel of ten representatives from a range of key stakeholder groups. The expert panel comprised:

Ric Bowl: Senior Lecturer in Social Policy School of Education, University of Birmingham.

Tina Braithwaite: Acute Solutions Project Manager, Sainsbury Centre for Mental Health.

Charlie Brooker: Professor of Mental Health ScHARR, University of Sheffield.

Martin Brown: Chief Executive Northern Centre for Mental Health.

Phil Confue: Director of Mental Health Services, Plymouth PCT.

Martin Humphreys: Senior Lecturer in Forensic Psychiatry, South Birmingham Mental Health NHS Trust.

Steve Onyett: Development Manager-Mental Health South West, NHSE-South West.

Edward Peck: Director of the Institute for Applied Health and Social Policy Kings College London (now Director, Health Services Management Centre, University of Birmingham).

Sue Wilson: Senior Research Fellow Department of Primary Care and General Practice, University of Birmingham.

Til Wykes: Professor of Clinical Psychology and Rehabilitation, Institute of Psychiatry, London.

The expert panel met on two occasions during the study period (in months two and five of a six month study). The role of the panel was to recommend appropriate search strategies and terms, recommend key documents to be included in the review, make suggestions concerning the direction of the review, explore emerging themes and issues and read and comment on draft booklets.

Structure of the review

Cases for Change consists of this initial booklet, which describes the background and methodology of the review, summarises the main findings and suggests areas for future research/policy development. There are also nine further booklets which include an overview of mental health policy, primary care, community services, hospital services, forensic services, partnership working, user involvement and anti-discriminatory practice. The final booklet reviews the literature with regard to a range of miscellaneous issues that do not fit neatly into any of the previous topics: support services for carers, direct payments, responses to self-harm and the role of new technology.

Each of the main booklets begins with a 'background' section explaining why the topic concerned is significant and relating it to developments in services outside mental health. Next, the 'cases for change' section explores the key themes that have emerged from the literature review, before a 'further information' paragraph lists resources where people can go to find out more about any given topic. Sometimes these are printed documents, but a range of web-based sources have also been identified for ease of access. While the full text of internet documents sometimes has to be purchased from the authors, many of the sources can be accessed and printed off free of charge. Abbreviations are listed in Appendix A and technical terms are explained in more detail in Appendix B. At the end of each of the main booklets, there are critical commentaries by service users and practitioners/managers/policy analysts from different geographical regions. These commentaries are not necessarily representative, but are intended to emphasise that different groups of people have different priorities and identify different cases for change. All contributors have been encouraged to be as challenging as possible and, where they disagree with interpretations, to say so.

Summary of the review

The key findings from Cases for Change fall into two different categories:

- Specific findings that are set out in each individual section.
- More general overarching themes and issues that emerge consistently throughout the review.

1. Specific Findings

In mental health policy as a whole

- There is a difficult balance to strike between risk and vulnerability of people with mental health needs, a key theme of many policy initiatives and most recently in responses to the draft Bill (TSO, 2002).
- The trend towards more accountable health and social care requires a significant cultural shift, will take time to implement and needs to be accompanied by local flexibility.
- The rapid pace of change can be challenging and changes will take time to bed in.
- Mental health services are inextricably linked to wider issues such as unemployment and social exclusion.

In primary care:

- There is a need to develop more integrated ways of working, but this is dependent upon primary care's commitment to mental health as an issue and the creation of a culture of

mutual respect between primary care and specialist mental health services.

- Practice nurses could play a greater role in developing primary care mental health services, perhaps through greater involvement in the care of people with serious mental illness and the development of new services using a chronic disease management model.
- Many of the changes that this review has highlighted depend on developing and cascading new integrated ways of learning together.
- The views of service users need to be taken into account and acted on when remodelling existing provision and developing new services.

In community services:

- There are complicated debates within the literature about the merits of functionalised community mental health services such as Assertive Outreach and generic Community Mental Health Teams (CMHTs).
- There may be a range of practical difficulties to overcome in establishing services such as Home Treatment or Early Intervention.
- Debates are ongoing on the role of Community Psychiatric Nurses (CPNs): should they be focusing on the needs of people with common mental health problems in primary care or on the needs of people with serious mental illness in specialist services, or both?
- There are a number of good practice examples cited in the literature which may provide alternatives to hospital admission.

In hospital services:

- There is significant pressure on acute psychiatric beds, with services forced to maintain waiting lists, send people home on leave and place users in services outside their local area.
- Existing hospital beds may not be being used appropriately, and a whole systems approach that considers the full range of mental health services is required.
- Many service users have extremely negative experiences of hospital and find the hospital environment stressful rather than therapeutic.
- Hospital services have tended to be neglected in the literature as a result of the focus on community services.
- Recent acute inpatient care guidance (Department of Health, 2002e) established an infrastructure for continuous improvement in order to offer therapeutic experiences for people while in hospital and develop inpatient care as an integrated part of health and social care.

In forensic mental health care:

- Many people in prison have unmet mental health needs. This raises key questions as to whether prisons are equipped to fulfil the role that they are being asked to play in supporting people with mental health problems.
- Some existing secure beds are being used inappropriately, with significant capacity problems and substantial delays in transferring people between different levels of security.
- There is a need for much more effective partnership working between health care, social care and the criminal justice system. MAPPA may have a role to play here.
- There is a need for further research into long-term outcomes and people's journeys through secure services, community provision, preventative work and the opinions and experiences of users and carers.

With regard to partnership working across health & social care:

- Partnerships are a crucial government priority, but are particularly significant in mental health for a range of financial, political and practical reasons.
- Despite this, there are substantial barriers to partnership working.
- Local partners will need to adopt an incremental approach, utilising whichever avenues they feel will help them as they work towards developing more effective partnerships.
- The existing literature is limited by the absence of a user perspective and a failure to focus on partnership working in areas with a poor history of joint working. Many documents also fail to consider some of the potentially negative aspects of partnership working, and tend to be intuitive rather than evidence-based.

With regard to user involvement:

- User involvement brings a range of benefits, harnessing the expertise of service users, building on their existing strengths and coping mechanisms, challenging traditional assumptions, suggesting new ways of working and increasing individuals' confidence/self-esteem.
- Despite this, there are substantial barriers to user involvement and progress has been patchy. In particular, much involvement has been tokenistic and fails to move beyond the level of rhetoric into practice.
- Progress will be helped by an inclusive values base of practitioners, a real commitment to involvement at an organisational and community level to learn how to get the practicalities right, and focusing on service users' strengths in order to maximise their contribution to improving mental health.
- Users need to be involved at every level of mental health services.
- There is a need to move beyond mental health services to consider users' position in wider society, educate the public and the media, tackle discrimination and promote social inclusion.

With regard to anti-discriminatory practice:

- Welfare services have not traditionally profiled discrimination on mental health grounds.
- Many women have very negative experiences of mental health services including mixed hospital wards.
- 'Black' people are over-represented in mental health services, tend to receive more coercive treatment and often find services culturally insensitive.
- The small number of documents on sexuality suggest that lesbians, gay men and bisexual people can face considerable discrimination and harassment within mental health services.
- There is a need for concerted action to tackle discrimination in all its forms, both within mental health services and within wider society.

With regard to emerging areas of service provision:

- Despite a growing awareness of the needs of carers in general, there is little evidence about the needs and wishes of carers of people with mental health problems and effective service responses.
- Direct payments have the potential to increase the choice and control of a range of user groups, but have yet to make a significant impact on mental health services.
- Deliberate self-harm is a significant issue

for many people. Despite recent national guidance, existing knowledge and service responses are limited.
- New technologies such as computer modelling, telephone help lines, videoconferencing and computer-based self-help packages may have a significant role to play in future mental health services.

2. Overarching Themes

There are also a number of common themes that run throughout the review. In particular, there are four main issues:

The need for a whole systems approach and partnership working

Individual booklets have suggested a need for a whole systems approach, with change based on a long-term and systematic consideration of the resources available and the balance of services required. Changes in one part of the service will require flexibility and responsiveness from other statutory and non-statutory sectors or the users' experiences of services will be fragmented and their journey through the mental health system disjointed. This is particularly true in areas such as community services, hospital provision and forensic mental health care, where the significant pressures which exist can only be resolved by taking a step back and examining mental health services as an interconnected whole. Thus, changes in acute care are likely to have a 'knock-on effect' for community provision, while successful forensic services will depend upon an appropriate spectrum of services being available to deliver appropriate care at the appropriate time to users with a range of different needs. Elsewhere, there is evidence that some of the issues at stake are so fundamental that only a systematic overhaul of existing provision will suffice. Thus, concerted action will be required across a range of services if effective partnership working is to be promoted, if users are to be fully involved in services and if discrimination is to be identified and rooted out. With many of the Cases for Change identified in this review, therefore, there are few 'quick fixes' and only long-term, whole systems approaches are likely to make a difference.

The importance of values

Crucially, many of the priorities for change identified in this review relate not only to the type of service on offer, but to the underlying values and attitudes of front-line staff, managers and policy makers. With many of the issues, service changes can help to improve the situation, but more fundamental reform will ultimately depend on much deeper changes in the culture of services. Thus, partnership working, user involvement, empowerment and anti-discriminatory practice all depend not only on the service structures in place, but on the values of individual practitioners. Changing values is likely to be challenging and will clearly have major implications for current mental health training and education.

Barriers to change

Many of the issues raised are extremely familiar and are longstanding problems that successive Governments and other national and local bodies have recognised and are challenging to address. Thus, there is a large and established literature on the limitations of hospital services, barriers to partnership working, the negative experiences reported by women and 'black' people and pressures on acute hospital beds. Despite this, many recent studies continue to emphasise and re-emphasise the same sorts of findings. This raises a key question: what is preventing change from taking place - if we know what the problems are, why haven't we been able to develop successful solutions?

Although it is beyond the scope of this review to answer such a question in detail, there are a number of potential responses:

- Is there the political will?
- Is there financial support to implement change?
- Are issues concerned a priority for workers?
- Do the challenges feel surmountable?

Whatever the reason, those wishing to implement planned change will need to draw on the wider literature about change management in order to turn this summary of the strengths and weakness of current mental health services into a practical and effective agenda for change (see the Policy booklet for further reading on change management).

The nature of evidence

Throughout Cases for Change, a wide range of evidence, ranging from systematic reviews and randomised controlled trials (types I and II research evidence) to observational studies and to the opinions of users, carers and practitioners (types IV and V) have been used. The inclusion of a broader evidence base has significantly strengthened this review and given voice to commentators who have often been overlooked when mental health reforms are being discussed.

Almost inevitably, such an approach raises a number of philosophical questions about the nature of 'evidence' itself:
- What is meant by 'evidence' and who decides what is to be treated as a 'valid' contribution? Whereas some people would see many of the documents in this review as 'anecdotal evidence', others would see them as 'human testimony.'
- Which voices tend to be the loudest when we debate the reform of mental health services?
- Which voices tend to be drowned out?
- Who decides which voices should inform policy and which should not?
- How can the expertise of users and practitioners be prioritised more effectively?

Overall, this review has emphasised the many and varied Cases for Change that emerge when an inclusive approach is adopted which seeks to listen to and value contributions from all those involved in mental health services - whether they be service users, carers, practitioners, managers, policy makers or academics.

Finally, this report should be seen as starting point and as a means to an end rather than an end in itself. Neither the research team nor the documents reviewed have all the answers, and it would be unrealistic to expect a simplistic and definitive solution to many of the issues raised in this review. However, by summarising the key issues that have emerged from the literature and by emphasising the diversity of opinion that exists within mental health services, Cases for Change can help to provoke a debate about the best way forward and the way in which different view points can be balanced in order to achieve mutually beneficial outcomes.

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Appendix A: Abbreviations

A&E	Accident and Emergency
CPA	Care Programme Approach
CSAG	Clinical Standards Advisory Group
CMHT	Community Mental Health Team
CO	Constant Observation
CTO	Community Treatment Order
DoH	Department of Health
DSH	Deliberate Self-harm
DUP	Duration of Untreated Psychosis
ECR	Extra-contractual referral
ECT	Electro-Convulsive Therapy
GMC	General Medical Council
GP	General Practitioner
HIV	Human Immuno deficiency Virus
HMSO/TSO	Her Majesty's Stationery Office/The Stationery Office
IPC	Integrated Primary Care
NCIL	National Centre for Independent Living
NDDP	New Deal for Disabled People
NHS	National Health Service
NHS SDO	NHS Service and Delivery Organisation
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
ONS	Office for National Statistics
PCG/T	Primary Care Group/Trust
PRiSM	Psychiatric Research in Service Measurement
RCT	Randomised Controlled Trial
SDO	Supervised Discharge Order
SSD	Social Services Department
TAPS	Team for the Assessment of Psychiatric Services
WHO	World Health Organization

Appendix B: Glossary of technical terms

This glossary seeks to explain some of the key terms used in this report. Wherever possible/appropriate, we have sought to quote definitions offered by the Mental Health National Service Framework (Department of Health, 1999a, pp.128-135). NSF definitions are denoted by an *.

Approved Social Worker (ASWs):* ASWs are social workers specifically approved and appointed under Section 114 of the Mental Health Act 1983 by a local authority social services authority 'for the purpose of discharging the functions conferred upon them by this Act'. Among these, one of the most important is to carry out assessments under the Act and to function as applicant in cases where compulsory admission is deemed necessary.

Assertive Outreach:* An active form of treatment delivery: the service can be taken to the service users rather than expecting them to attend for treatment. Care and support may be offered in the service user's home or some other community setting, at times suited to the service user rather than focused on service providers' convenience. Workers would be likely to be involved in direct delivery of practical support, care co-ordination and advocacy as well as more traditional therapeutic input. Closer, more trusting relationships may be developed with the aim of maintaining service users in contact with the service and complying with effective treatments.

'Black' people: A term used to describe the common experiences of those who encounter racism as a result of the colour of their skin. While this term is useful in emphasising the shared experience of racism, it should not distract from the fact that 'black people' are an extremely diverse group and should not overlook the fact that many white minority ethnic groups may also experience racism (such as Irish people).

Carers: Family members, friends of neighbours who 'care' for someone with a mental health problem. This term is usually used in services for people with physical impairments where some sort of physical caring task is required. As a result, its appropriateness is open to question in mental health, where the nature of the 'caring' relationship may be more emotional than physical and where people define themselves as friends and as family members rather than as 'carers.' Despite this, 'carer' is the term used in most of the literature and in official policy documents/legislation and has been retained in this review.

Care Management:* A system of organising care for vulnerable adults by local authority social services departments. It involves assessing needs, care planning, the organisation of care packages within available resources, monitoring and review and close involvement with service users and carers. For mental health service users it should be integrated with the Care Programme Approach.

Case Management: A user-centred approach to the coordination of services to meet the needs of vulnerable individuals. It targets older people, disabled people or those with mental health problems, enabling them to live in the community by accessing appropriate help. Its goals are continuity of care and individualised support through assessment, care planning, intervention, monitoring and review. There are many models of case management and that implemented in the UK is termed care management (Davies, 2000).

Care Programme Approach (CPA):* The CPA provides a framework for care co-ordination of service users under specialist mental health services. The main elements are a care co-ordinator, a written care plan, and at higher levels, regular reviews by the multi-disciplinary health team and integration with the social services care management system.

Clinical governance: An approach to quality based on five overlapping activities – quality improvement, clinical audit, evidence based practice, risk assessment and management and continuous professional development.

Cognitive behaviour therapy:* A form of psychological treatment based on learning theory principles used mostly in depression but increasingly shown to be a useful component of treatment in schizophrenia.

Deliberate Self-harm (DSH): This term is poorly defined in the literature and is often used to describe people who have harmed themselves deliberately in any one of a number of ways (e.g. by cutting themselves, burning themselves or poisoning themselves). For many service users and practitioners, 'self-harm' refers to actions such as cutting, where the person harms themselves with no intention of killing themselves. This can often be a deliberate coping mechanism, enabling the person to feel a sense of relief or to express built-up emotions. Unfortunately, the wider literature tends to confuse this with attempted suicide and the term is used imprecisely. To the authors, this seems to confuse two very different phenomena: self-harm (as a means of coping/survival) and attempted suicide (as a means of trying to kill oneself).

Early Intervention: A service designed to intervene at an early stage in first episode psychosis for people aged 14 to 35. This is important as the first few years of psychosis carry the highest risk of serious sustained physical, social and legal harm.

Electro-Convulsive Therapy (ECT): A physical treatment used predominantly for people with severe depression which involves the passage of an electric current across the brain.

Extra-contractual referral (ECR): Admitting someone to hospital outside the area, often when all available local beds are full. This can be very expensive and is sometimes unpopular with service users. (Also known as Out of Area Transfers or Individual Patient Placements).

Home Treatment:* Treatment may be offered in a patient's home rather than in clinical settings, either by a separate team or by the community mental health team. Frequent home visits by various members of the multi-disciplinary team can lead to an avoidance of some hospital admissions and provide support to carers. Such services should be available at weekends and in evenings as well as during office hours. (Also known as Crisis Resolution).

Keyworker:* A worker with responsibility for co-ordinating CPA reviews for mental health service users with complex needs and for communicating with others involved in the service user's care. (Also known as care co-ordinators).

National Service Framework (NSF): A government document setting out national standards and service models of care for specific user groups. Early NSFs have focused on groups such as people with mental health problems, older people and people with coronary heart disease.

Supervised discharge:* Under the Mental Health (Patients in the Community) 1995 consultant psychiatrists may apply for powers of supervision following discharge from hospital. A supervisor, typically a community psychiatric nurse acting as care co-ordinator, has the power to 'take and convey' the patient to a place of treatment, but not to treat them.

Bibliography

This bibliography is divided into three sections:

- Section one contains the literature included in the Cases for Change review.
- Section two contains wider literature referred to throughout this review.
- Section three contains Acts of Parliament/Bills referred to throughout the review.

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Human Rights Act 1998

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Mental Health Bill: Consultation Document 2002

Mental Health (Patients in the Community) Act 1995

NHS and Community Care Act 1990

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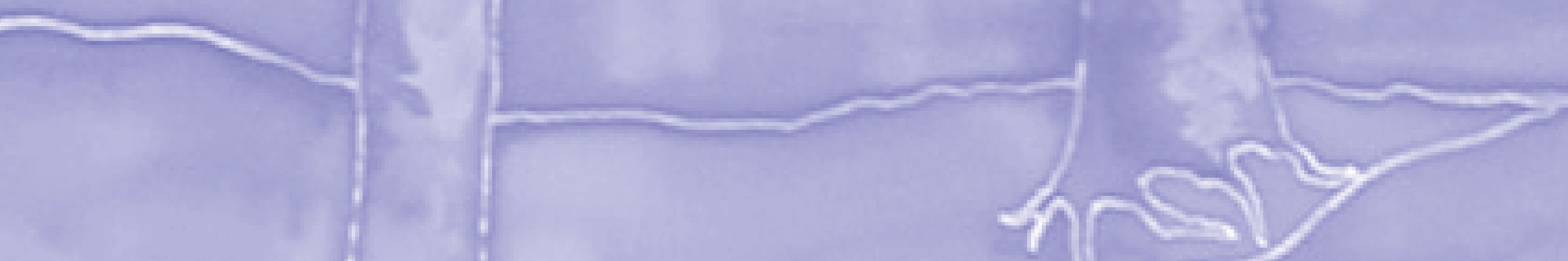
Many of these Acts of Parliament are available on the HMSO website together with detailed explanatory notes (www.hmso.gov.uk).



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