



*Creating positive change in services for people with
severe and long-term psychiatric disabilities*

Better Futures

Better Futures is a two-year initiative to encourage the development of effective, comprehensive local services which are responsive to the needs and wants of users and their families.

The King's Fund Centre will:

- work in partnership with a small number of selected localities in England and Wales to improve the availability, accessibility, relevance, cultural sensitivity and co-ordination of services for people with long-term needs;
- disseminate and publicise experience gained in the localities by developing resource materials and guidance which will be helpful to other authorities.

The participating localities will have the opportunity to take part in a national network group to share information, learn from each other's experience and make this information accessible to other localities. The network will act as a focus for generating support and commitment to working with people with long-term needs and developing ideas, strategies and designs for improved services.

Why is this initiative needed?

There is widespread concern about community care which was first promoted as a national policy over 30 years ago. Many people have been discharged from long-stay wards only to end up in large institutional settings where they continue to receive inappropriate care. Others are trapped in a "revolving door" of inadequate support and care in the community interspersed by emergency admissions to hospital. What has gone wrong?

- *Lack of direction.* There is little agreement amongst statutory agencies, voluntary organisations, users and families about the philosophy, objectives, content and practice of community care.
- *Shortage of resources.* The finance to develop new community services is still tied up in the old Victorian hospitals which are increasingly expensive to maintain and staff. New resources are scarce and hospitals consume a disproportionate part of the mental health budget.
- *Divided responsibilities.* No one agency provides all the help that users need.
- *Services are not user led.* Services are based on professional perceptions of need rather than the experiences of users. Consequently, people who use services often experience them as inappropriate or unresponsive.
- *Difficulties in collaboration.* Joint planning can seem like a bureaucratic process which deters people with first-hand knowledge of local needs from participating.
- *Low priority for people with long-term needs.* In many areas community mental health services serve people who respond to short-term interventions rather than those who need ongoing help and support.
- *Problems in staff development.* Professional training often does not equip staff to work in the community with people who experience long-term mental health difficulties. Lack of support and supervision can lead to burnout even in staff with a high level of commitment.
- *Poor staff morale.* Many workers feel devalued because of successive reorganisations in statutory agencies and uncertainties about the future of mental health services. Defensive attitudes have contributed to difficulties in the development of inter-disciplinary work.

The policy context

Better Futures is taking place in the context of major changes in health and social services. Although implementation has been delayed, "Caring for People" reaffirms the policy of community care and upholds the ideals of choice and independence for people with disabilities.

"Working for Patients", the NHS White Paper, has implications for mental health units which decide to opt out of local health authority control. General practitioner budget-holding may alter the pattern of purchasing, but it is too early to say.

There are several opportunities arising from the current situation:

- The NHS care programme approach and local authority case management systems, if developed as a complementary rather than a parallel system, should ensure that individuals receive an integrated service.
- The mental illness specific grant, however limited, is a new source of finance for local mental health services.
- Supplementary benefit payments can still be used to help finance ordinary housing with appropriate support for people leaving psychiatric hospitals.
- Local authorities must consult users, carers and representatives of black and ethnic minority groups in drawing up community care plans.
- If self-governing trusts are successful, more mental health units may consider them as a way of protecting funds from the sale of capital assets for mental health services.
- Purchasers can potentially buy highly individualised, good quality services from a range of non-traditional providers e.g. user and carer groups, black voluntary organisations. The opportunities for innovation are exciting but depend on active development work.
- Social services departments can take a leading role in developing mental health services which are receptive to the views of users and their families and more responsive to their ordinary needs.

There is a real danger that the pace and scale of change may lead purchasers and providers to become over-involved in the mechanisms for achieving change and distracted from the task of improving the service. Better Futures will help localities to develop a clear strategic vision which can guide choices and priorities and facilitate creative use of opportunities in the NHS and Community Care Act.

A focus on people with long-term needs

Service providers have experienced significant challenges in providing local services for people with ongoing needs, particularly for those who have not been institutionalised by long stays in hospital. In the transition from hospital to community services, they are particularly vulnerable to being neglected or inadequately served.

Any definition of people with long-term needs is arbitrary. Our working definition, which is drawn from a number of existing sources*, will be refined and developed during the course of the initiative for use in other localities. Better Futures is concerned specifically with improving opportunities and services for people:

who may have functional difficulties associated with severe emotional distress e.g. they may have problems with personal care, looking after their home, managing financial affairs, finding and keeping work, arranging and participating in leisure activities and coping with personal relationships

and/or

who have had a long history of involvement with mental health services i.e. a continuous in-patient stay of more than 6 months or multiple admissions in the last five years with significant health and social care needs.

It is important to recognise that people with long-term difficulties also have strengths and capacities that can be built on. Each individual has their own history, wishes, interests, skills and talents that should be taken into account when planning and delivering services.

The level of the difficulties that they experience may fluctuate so that services need to be able to respond flexibly.

A good local service should be *inclusive* and able to respond to the needs of all its population. Better Futures will help purchasers and providers to find more imaginative and sensitive ways of responding to the needs of people with long-term difficulties including minority groups with mental health needs such as black people, homeless people and people with challenging behaviour.

* NIMH *Definition and Guiding Principles for Community Support Systems*, Rockville, Maryland, 1980, and materials produced by N. Derbyshire Health Authority/ Derbyshire County Council Joint Planning Group – Mental Health, 1990.

Shared values

Clear values, which are understood and shared locally, are essential to the development of comprehensive services. Lack of consensus can lead to disagreements between providers, users and carers about what services are needed and how they should be provided and evaluated.

Better Futures starts from the assumption that all human beings are of equal value whatever their level of disability. People with long-term needs are entitled to appropriate help with their problems and to experience a satisfactory quality of life. This means that services should reflect these basic values:

Individuality: Each individual is unique and will have different needs depending on their strengths, difficulties, gender, sexuality, culture and race;

Choice: Everyone needs to be listened to and to make choices about their lives;

Participation: Each individual has the right to be visible in the community where they live and to participate in ordinary community life;

Independence: People have the right to live as independently as possible, although a great deal of support may in practice be needed to achieve this;

Respect: People are entitled to privacy and dignity in their everyday lives and to have their experiences acknowledged and recognised;

Growth: Everyone has the potential for change and growth whatever their level of disability.

Services based on these values will respect individuality and offer variety, continuity and co-ordination. They will be provided flexibly in ways which do not demean the recipient and respect cultural and racial sensitivities.

An early task of the Better Futures initiative will be to help the partnership localities define appropriate values for their services drawing on materials produced by the King's Fund Centre, MIND and other groups.

A more responsive service

There is general awareness that users, carers, voluntary organisations and black and minority groups often have a clearer picture of local needs than service planners and managers. They may also be aware of community resources and networks which can add to the stock of opportunities and services available locally.

Users, in particular, find it difficult to have their voice heard in the development of new services and service providers find it equally difficult to involve them in planning and decision-making. Black users and their families are often totally ignored. Yet change will only happen when providers start listening to users.

Local services are dominated by acute in-patient psychiatry and there are many gaps in service provision. There are few work opportunities for people leaving hospital although this would help users to recover their place in society and shed the stigma of mental distress. There is often inadequate support and care for people who need help in coping with everyday life and in overcoming isolation. Early intervention needed to enable people to stay out of hospital is rarely available so that people become trapped in a cycle of avoidable admissions and inadequate aftercare. Alternatives to hospital admission are rare.

Better Futures will help participating localities to develop different methods and strategies for listening and responding to users, carers and people from racial minorities.

There is also widespread recognition that users, carers and people from racial minorities have a contribution to make to service evaluation. They have direct experience of services and are in a good position to assess its quality. Current changes in health and social services suggest that quality can be secured through specifying minimum standards when contracting for services and monitoring these by inspection. Although these mechanisms may be useful, services have their greatest impact on users and they are a major source of untapped information about the quality of services. Better Futures will help localities to develop appropriate ways of involving users, carers and people from racial minorities in evaluation and to share these strategies with others.

A functional approach to planning

Moving from a service based on large institutions has proved to be an immensely difficult and complex task. A few hospitals have closed and some innovative projects have developed, but overall progress towards local systems of care has been slow. In the last few years, the King's Fund Centre has developed a model with other agencies for designing a mental health service system known as DISC (Developing and Implementing Services in the Community), based on the American Balanced Service System*. A number of localities have already found this model useful in planning a local service and it will be incorporated into the "Better Futures" initiative.

Mental health service plans, based on numbers of beds and day places, make implicit assumptions about need. It is often difficult to tell from a plan what needs it is meeting and how success will be judged. DISC is a framework for making needs explicit so that purchasers and providers can specify the functions of an effective mental health system.

The DISC service functions:

identification — service providers need to know how many people are in need of a service locally. This function may involve imaginative outreach services to people who traditionally avoid the mental health system, such as black and minority groups and homeless people with mental health needs.

case management — a single worker or team should be responsible for finding out what an individual with long-term difficulties wants and needs, making a plan for co-ordinating the inputs of different workers and agencies and monitoring the impact of services.

crisis stabilisation — individuals can rarely find help in the early stages of a crisis and may have to wait until their distress becomes so severe that they are admitted to hospital. An emergency admission to hospital can be very traumatic and the stress may extend to family and friends. A small in-patient acute unit, offering high quality care, is an important part of a local mental health system but should not be the only help available in a crisis. Other solutions may be a peripatetic team offering 7 day, 24-hour crisis stabilisation, a crisis house offering short-term accommodation and support and/or a telephone advice and consultation service.

maintenance — crisis services need to be supplemented by on-going help and support which can be provided flexibly as needs change. Some of the basic human needs included in this functional category:

* Gerhard, R J, Dorgan, R E and Miles, G G, *The Balanced Service System: a Model of Personal and Social Integration*, Clinton, Oklahoma, Responsive Systems Associates Inc, 1981.

- housing
- food and warmth
- money
- work
- leisure
- love and friendship

In addition, special help may be needed with:

- personal care
- household tasks
- help with mental and physical health problems
- personal safety
- advocacy and protection of rights

growth — people also need new opportunities and challenges, even though personal change and growth may occur very slowly. Growth could include learning new skills, catching up on basic education e.g. literacy or by going on holiday.

A functional approach enables local people to come up with imaginative solutions to meeting individual needs rather than being constrained by ideas about what the service ought to provide:

- someone who finds it difficult to keep appointments could be visited at home or wherever they are currently living, even on the streets;
- a black person might join an art class at the local West Indian community centre rather than go to art therapy sessions at the day centre;
- a voluntary organisation might set up a crisis house as an alternative to hospital admission for people who are in need of short-term intensive support.

Each function may be developed separately and incrementally but all five need to be present before a mental health system can be said to be in place.

A functional service audit can be carried out to check what is available locally and to identify gaps in service provision. Better Futures will help localities to establish their existing baseline provision using this approach.

How Better Futures will work

The King's Fund Centre is offering a package of 20 days' consultancy per year, divided between the Centre and the field, over a two-year period to a small number of localities who wish to participate in the Better Futures initiative. A King's Fund Centre officer will work with a group of key decision-makers in each locality to help develop a comprehensive range of user-led, opportunities and services. The group should include people with the authority to commit resources, including purchasers and providers, and people with particular expertise in mental health, such as users and key professionals, including psychiatrists.

Better Futures is part of the work of the Community Living Development Team, directed by Dr. Roger Blunden. Applications to take part in the initiative are welcomed from health authorities and local authority social services departments. Details of how to apply are given in the attached letter.

The work in each locality will be carried out through regular meetings of the Better Futures group, workshops and seminars. The King's Fund Centre can offer:

- information about mental health service developments in Britain and abroad;
- facilitation skills;
- a commitment to user-led services;
- a higher profile for local services;
- access to advice and support from contacts in other services;
- an outside perspective on local issues.

The exact content of the development work in each locality will be decided by negotiation following an extended local visit to meet managers, practitioners and users and become familiar with existing services. Short and long-term goals will be agreed and regularly reviewed. These will form the basis of a contract between the locality and the King's Fund Centre.

Specific work likely to be covered during the two-year period includes:

- helping local decision-makers achieve clarity and agreement about the values, objectives, priorities and content of the local mental health system;
- assisting local decision-makers to explore alternative ways of implementing plans and to produce effective strategies for action;
- building commitment to people with long-term needs, including people who are difficult to reach, and exploring better ways of meeting their needs and developing their potential;
- developing effective ways of involving users, carers and people from racial minorities in planning, decision-making and evaluation;

- creating a local learning system which permits staff at all levels as well as users and carers to contribute to the development of the service and monitor its progress;
- using this experience to produce resource materials and guidance, in partnership with the Better Futures localities, which will be of help to other health and local authorities.

Localities involved in the Better Futures initiative are likely to give prominence to quality issues in developing and running their service. One beneficial by-product of Better Futures may be that, in a time of staff shortages, localities may find it easier to recruit and retain workers.

At national level, the work will be directed towards generating and supporting greater commitment to community care for people with long-term needs by documenting and publicising the outcomes of our work with localities, particularly examples of good practice.

A national network group will be set up to enable the partnership localities and other interested localities to share information about successes and problems in service development. The network will be encouraged and assisted to provide national and local leadership in developing and disseminating ideas, information and good practice in services for people with long-term needs.

It is hoped to evaluate the initiative although no firm decisions have been made. Discussions are under way at the King's Fund Centre about the best way of carrying this out and further funding will be sought.

For further information contact:

Community Living Development Team
King's Fund Centre
126 Albert Street
London NW1 7NF

Tel: 071-267 6111

© King's Fund Centre, 1990

