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# Changing futures

## *Housing and support services for people discharged from psychiatric hospitals*

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## for people discharged from psychiatric hospitals

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# CONTENTS

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## INTRODUCTION

This project paper has been written for staff concerned with resettling people who are being discharged from long-stay hospitals or who are developing housing schemes for people with serious psychiatric disabilities living in hostels or with their families.

In these times of great change in the mental health services, this project paper attempts to distil the lessons from current examples of good practice so that they may be more widely applied and learnt from. Nothing in this paper is radically new; rather we have taken a fresh look at some key issues and in doing so, have found it most useful to draw upon the 'an ordinary life' framework.(1) The principles upon which this project paper is based are concerned with supporting individuals in living as ordinary a life as possible.

The major impetus for this work is a commitment to improving the lives of people with a long-term mental illness. The historical cycle of neglect, reform, and then neglect of services for mentally ill people has been well documented by others.(2) And reforms instituted by the move to community-based care must not be allowed to lead, yet again, to neglect. The earliest indications from hospital closures have been mixed. Some people have achieved a quality of life denied them for years in an institution; others, though, have found themselves in an uncaring community with inadequate support services and have drifted into poverty and isolation.

This paper, then, is concerned with capitalising on these current changes to provide a genuinely innovative, exciting and responsive mental health service. To this end we have been careful of the language used. The word 'patient' rarely appears in an attempt to reflect the new status of people who use mental health services. We have also tried to eliminate any jargon so that the paper can be read easily by a wide range of people. We feel these are important issues which need further discussion and debate.

There are two points on which we could rightly be criticised. First, we have chosen to focus on the individual who uses services. This has meant we have not separately addressed the needs of families and other informal carers who are doing most of the work in supporting people with a mental illness in the community. This is not to deny the difficulties and problems which carers face, but initially we felt that our primary focus should be the user and his/her relationship with the mental health service. Second, we have not specifically looked at the needs of users from black and ethnic minority groups. Our whole approach is one based on care of the individual and seeking valued ways of supporting them. We hoped this approach would take into account the needs of people from different cultural backgrounds but, in retrospect, this may be an issue which should have been separately addressed.

The paper has been designed so that each chapter can be read on its own. However, there is an overall theme: the development of community-based housing and support services. We hope this will be a useful contribution to the growing field of literature and research on providing high quality services and an improved and more valued life for people with psychiatric disabilities.

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| **Rose Echlin** | Senior Information Officer, Good Practices in Mental Health, London. |
| **Steve Hill** | Coordinator, MIND in Waltham Forest/Forest Community Project, London. |
| **Helen Smith** | Senior Project Officer, Mental Health Services, King's Fund Centre, London. |

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# CHAPTER 1

## THE NEED FOR VALUES IN A MENTAL HEALTH SERVICE

Some people in our society experience severe psychological disturbances at various times in their lives. The frequency and duration of these disturbances vary greatly with each individual, as does the nature and expression of their mental distress. Under the overall heading of mental illness, these disturbances have been variously named as schizophrenia, psychosis, manic depression, and so on. The major common themes running through these people's lives have been the long-term nature of the disability, stabilisation through the use of drugs (usually major tranquilisers) and a significantly high degree of contact with mental health services.

The very nature of psychiatric disabilities poses a great challenge for service providers. People in mental distress may find it difficult to organise their lives so that they can use the services available to them. They may need help outside office hours when the service providers are not available. People who act in ways that are very different may experience major conflict with family and friends. This disruption of personal relationships may further exacerbate someone's distress.

In the past, long-term solutions have been hard to find. In the absence of a definitive answer, people were placed in institutions that at least provided custodial care, even if they did not 'cure' mental illness. More recently, however, there has been a recognition that institutional care is inappropriate for people with long-term mental health problems and may, in fact, further disable them. The effects of long-term institutionalisation are well known - apathy, self-neglect and loss of motivation. Not surprisingly, institutional living cannot provide individual care for large numbers of people. The loss of control over their own lives, restricted opportunities and lack of power have an effect on people's behaviour. The result may be a deterioration in daily living skills, leading to the assumption that the person is now incapable of living outside hospital. However, the development of psychological and social models of care, the growth in the range and variety of professional skills and the advent of psychotropic drugs, have led to a questioning of this assumption. For the last thirty years government policy has been geared towards closing long-stay psychiatric hospitals. The reality of community care is now very much upon us, but for many reasons this model of care is failing to emerge as a more appropriate and responsive alternative.

Many people who have been discharged from long-stay hospitals during the reforms of the last decade, and others who would have been given shelter in them, are now either living in other types of institution or on the margins of society. People have been discharged to unsupported families or left to fend for themselves.(1) Alternative networks of support and care have proved difficult to develop. Homelessness or prison have become the unacceptable outcomes for growing numbers of discharged people. This is not to deny the excellent efforts of some projects and schemes that demonstrate good practice in this field, but these tend to be isolated examples.

We are facing a dilemma. The poverty and inappropriateness of life in long-stay hospitals has been rightly condemned for people with long-term psychiatric disabilities. Yet the poverty and difficulties of living in unprepared and unaccepting communities is equally unacceptable to people who use services and those who work in them. This dilemma confronts us with basic questions that urgently need to be addressed. What are the needs of people with long-term psychiatric disabilities and how can they be met by mental health services? The answers to these questions will be based on our (often unconscious) values as to who the people are, and our assumptions about what caused the problem and what might solve it.

## Negative images of mental illness

In the field of mental health there are no commonly agreed values or assumptions about the nature of mental illness. Views about the cause range from seeing it as a sane response to an insane world through childhood trauma or heredity, to biochemical changes in the brain. Each of these assumptions brings with it very different responses as to how the person and their family should be helped or treated. If we start from the viewpoint that one of the main problems that people with long-term mental illness have to face is the attitude of other people towards their illness, a whole new set of options becomes available.

The Origin and Nature of our Institutional Models(2) identified how people with substantial differences from the majority of us have historically been stereotyped as being:

a menace
less than truly human
objects of dread
trivial
objects of pity
burdens of charity
sick
a commodity.

Each of these stereotypes has a package of typical responses:

- If it is believed that people with a mental illness are a menace or dangerous, then it seems justified to segregate them from the rest of us and apply controls and constraints on their behaviour.

- If the person is viewed as less than human then it is unlikely they will be treated with respect and dignity and rights and privileges will be witheld from them.

- Our response to objects of dread is to shun them and put them at a distance.

- Trivia is something not to be taken seriously and is often a source of entertainment.

- Being responded to as an object of pity and a burden of charity will require the recipient to respond in ways which will attract and promote the benefactor's interest.

- If the person's problem is believed to be an illness which requires special treatment and care, the specialist providing them may claim unusual responsibilities for the person and feel justified in denying them certain opportunities and rights until they are deemed to be ready for them. If a cure is unavailable it may be rationalised that the person should be kept in custodial care until one is found; experimental treatment methods and regimes may be tried out on them.

It can be seen that all these responses have been part of the institutional model of care. In considering these stereotypes, it becomes easier to see why a new community model of services may have difficulty moving away from the attitudes and assumptions built into institutional care. **If we are to develop a new service, the values and assumptions it is based on must be explicit.** We need to develop a clear understanding as to why the service model we are moving away from is no longer acceptable and why we are investing in community care.

## Breaking the vicious circle - the principle of normalisation

If we are sincere in our desire to improve the quality of services for people with long-term disabilities and their families, then we will need to consider what problem we are trying to address. The way in which the person's problem is defined will have an influence on the service provided for them. Narrow definitions based solely on diagnostic catagories will restrict the number and type of solutions which might be attempted. By expanding our viewpoint to include a person's social functioning we bring many more options to bear and come nearer to addressing the problem that the person, and community, experience (see Figure 1, page 14).

> **The goal of a mental health service can be briefly stated as facilitating an individual's personal and social integration. This would mean enabling a person to achieve their optimum level of social functioning while they live, work, and relax in the least restrictive/protective environment possible.**

In services for people with a mental handicap the principle of normalisation has proved to be a useful foundation for planning and running services; it also provides the basis on which services can be evaluated. Although the principle has mainly been associated with mental handicap services it does generalise to other groups who have long term care and support needs and are therefore at risk of being thought less valuable than others. People who have long-term psychiatric disabilities are such a group in our society.

A working definition of the principle is offered by O'Brien and Tyne.(3)

> **'The use of means which are valued in our society in order to develop and support personal behaviour, experiences and characteristics which are likewise valued.'**

The word 'normal' does not occur in this definition; this is important because the principle does not imply that people would be made normal, but that services for people who are in danger of being devalued need to ensure that they do not add further to the negative perceptions that other people may have of the people using the services.

The authors state that:

> 'This definition calls attention to two aspects of any service:

1 WHAT THE SERVICE DOES (the "means" in the definition), including:

   the **physical setting** used, eg, buildings and facilities;
   the ways in which people are **grouped** for various purposes;
   the **goals** or purposes of the service;
   the **activities** selected to meet those goals and the way they are timetabled;
   the **people** who provide the activities and control their development;
   the **language** used to describe the service, its activities and the people it serves.

2 WHAT THE SERVICE ACTUALLY ACHIEVES FOR THOSE IT SERVES ("personal behaviour, experiences, and characteristics" in the definition):

   the social and other **skills** which people develop;
   the personal **appearance** of the people;
   the **quality and variety of the choices** in life which people have;

> This includes choices of living arrangements, educational opportunities, leisure time pursuits, work and other opportunities to take part in the lives of natural families and communities.

The principle of normalisation, then is concerned with where the service is going and how it is going to get there.'

## A more responsive service

In a mental health service based on this principle the decisions to determine the selection, provision and termination of services would be based on the person's ability to function in society rather than on a narrow definition of clinical pathology or diagnostic category. Assessment of the individual would also be used to develop a personal plan and to measure the outcome of the service. By shifting the focus of the service from the people's pathology to their social functioning, our range of responses is increased. At the present we cannot 'cure' severe psychiatric disabilities, but there are a number of well-tried interventions that can enhance people's social functioning and improve their quality of life.

The way of working directs the attention of service providers towards ensuring that they always choose the most valued way to meet people's special needs. It does not set some standard as a mould into which everybody must be made to fit.

The decision as to where people are to receive any necessary service will depend on the capacity of their 'natural' environment and social network to tolerate and support them. This may be in a range of settings, from the most protective - a hostel or hospital - to their own home. In order to maintain them in their own home they may only need to be linked to a domiciliary service; in addition relatives and friends may need to have their support augmented by services such as home help, meals on wheels, a visiting psychiatric nurse or social worker. Where a person does not have a social network, one might need to be devised in order to sustain him or her in the community. Sometimes it is not possible for a person to be sustained in the community by a natural social network, even when this is augmented by other support systems; it may be necessary to provide for his or her needs in a sheltered or protective environment (see Figure 2, page 15). Whatever the environment, the personal service plan should indicate how the service will enable him or her to join or be sustained in a natural social network.

## Accomplishments

O'Brien(4) has identified a number of key accomplishments or goals of a mental health service which arise from the principle of normalisation.

### 1 Community presence

The essential purpose of a mental health service is to enable people to achieve personal and social integration. One object is to help people develop and maintain relationships with valued community members in ordinary settings. This requires that services be provided in the person's own environment, and within easy reach of familiar places, friends and relatives. The assumption underlying this requirement is that mental illness has a major impact on a person's social functioning. **Community presence is a precondition for social integration.** This means working towards a community mental health service which:

- does not reject people because of difficulties in meeting their specific needs;
- meets people's needs in the most familiar environments possible;
- develops community services and natural support networks for people presently living in hospitals;
- disperses facilities across its catchment area.

### 2 Protection of rights and promotion of individual interest

It is important that people receiving mental health services should be valued as full citizens with the same rights and responsibilities as others, entitled to respect and dignity. This will require working towards:

- ensuring that people's views are heard and if they are unable to speak for themselves, finding appropriate people to advocate for them;

- ensuring that there are appropriate procedures for processing complaints and resolving conflicts;

- treating people as individuals with dignity and rights;

- treating people as having something of value to offer.

## 3 Personal continuity

Through life people usually try to keep contact with their family and friends. A person using mental health services should experience a subjective feeling of continuity across time and across agencies. This does not mean that one service or agency should attempt to meet all a person's needs in or near one setting. **The effectiveness of a service is judged by its ability to support, not supplant, natural relationships in familiar neighbourhoods and community settings.** This means working towards:

- planned coordination of services to meet individual needs;

- enabling people to remain with their families and/or the neighbourhood community within which they are established;

- a commitment to planning and developing future services.

## 4 Continuous personal development

Through life we develop new interests, learn new skills and engage in new experiences. **A service is effective if it uses systematic methods to help individuals develop skills that are useful and meaningful in an ordinary community or neighbourhood.** Skills and characteristics are considered to be such if they have a significant impact on decreasing a person's dependency and/or they support the development of skills or characteristics which are valued by other community members. This includes working towards:

* the design and use of environments which will enhance social functioning;

* searching for and using more effective, appropriate teaching materials and methods;

* developing the abilities of staff and others so that they may assist people receiving services to learn valued skills and attributes.

## 5 Image enhancement

The general public often develops its attitudes about people who use services by the way they are portrayed by the service. **A service is effective if it actively promotes a positive image for people who use it.** The patterns of activity, the language and symbols used should promote the perception of people with psychiatric disabilities as ordinary human beings. This means working towards:

* developing awareness about the effects of our expectations on the quality of the service;

* offering life conditions which would be valued by other community members;

* using language and symbols which present people who use and depend on services as unique individuals.

## 6 Community participation

Usually as people participate in their local communities they develop a large number and range of relationships with others. **Community participation is the sum of the other accomplishments.** It means actively supporting people's natural relationships with their families, neighbours, and co-workers and, when necessary, helping each individual to extend their network of personal relationships to include increasing numbers of people who are not also socially or psychiatrically disabled. The service is effective if it increases the opportunities for people to be active participants with others in all types of community settings:

- supporting relationships between people with disabilities and non-disabled peers in ordinary community settings;
- influencing larger systems (for example, the employment market) to create new opportunities for people to participate in the community;
- assisting people to develop in new ways.

* * * * * *

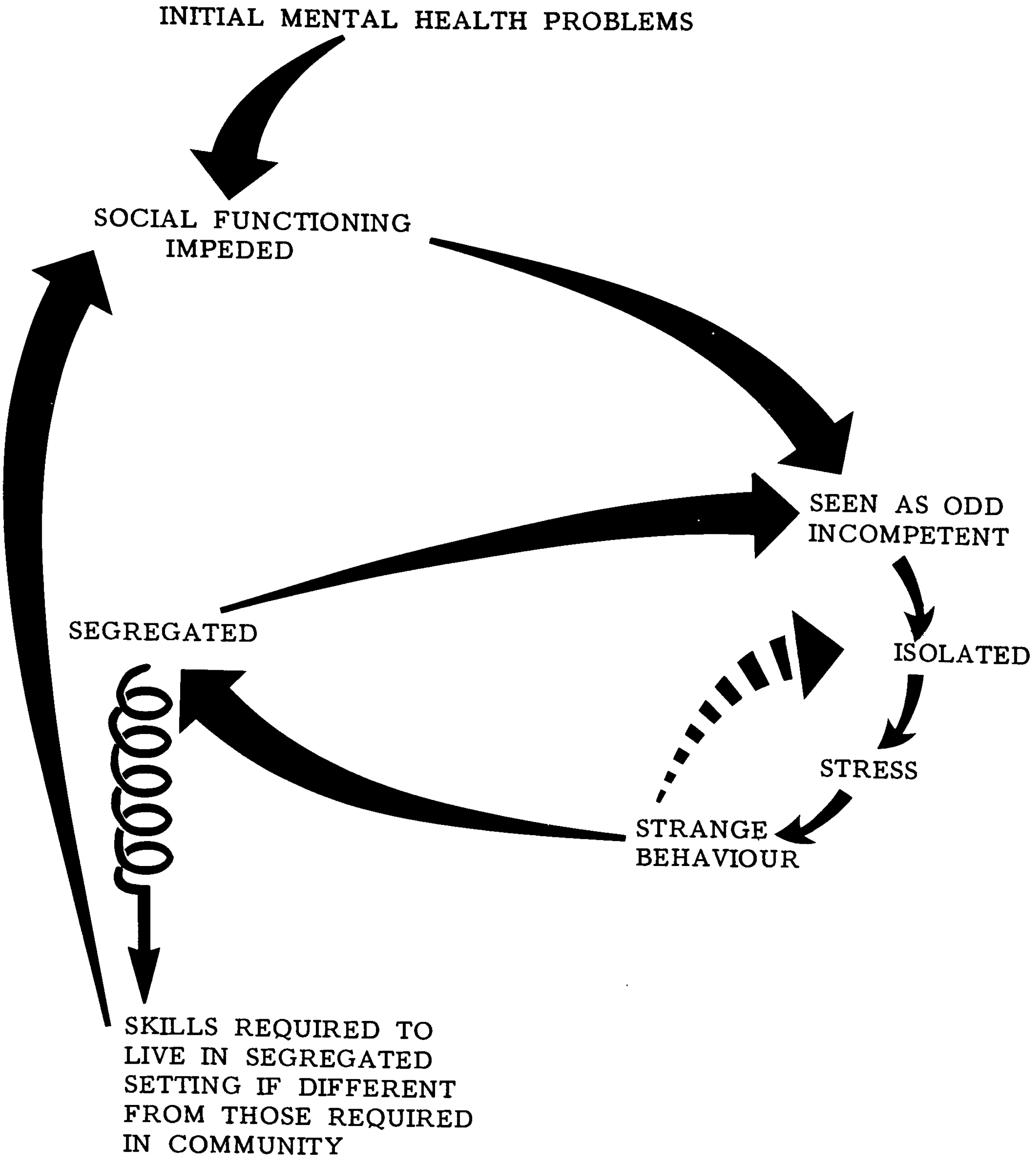

Figure 1 **THE VICIOUS CIRCLE**

| DESIRED CONSUMER DIRECTION | DESIRED PLANNING SEQUENCE | | SYSTEM | ENVIR-ONMENT |
|---|---|---|---|---|
| ◇ | 1 | PERSON RECEIVES REQUIRED SERVICES IN OWN HOME - SUPPORTED BY REGULAR SOCIAL NETWORK. | REGULAR HOME | NATURAL |
| ↑ | 2 | HOME ENVIRONMENT AND/OR SOCIAL NETWORK AUGMENTED BY ANOTHER AGENCY ie., HOME HELP, MEALS ON WHEELS etc., (PACKAGE OF SERVICES TO MAINTAIN PERSON IN OWN HOME). | AUGMENTED | |
| ↑ | 3 | IF PERSON IS UNABLE TO LIVE IN OWN HOME THEN AN ORDINARY HOME WITH BUILT IN SUPPORTS CAN BE DEVISED ie. GROUP HOME | DEVISED | |
| ↑ | 4 | PROFESSIONAL SERVICES AVAILABLE IF REQUESTED - IN ORDINARY HOME ie. SHELTERED ACCOMMODATION. | PROFESSIONAL ON SITE | |
| ↑ | 5 | PROFESSIONALS ON SITE 24 HRS BUT PERSON NOT GETTING ALL SERVICES FROM THIS SITE. | PROTECTIVE | INSTITUTION |
| ↑ | 6 | ALL SERVICES PROVIDED ON SITE | MOST SUPPORTIVE PROTECTIVE + + | |

Figure 2 RANGE OF SUPPORT AVAILABLE

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# CHAPTER 2

## PRINCIPLES INTO PRACTICE

Thus far we have argued for a community mental health service that is based on explicit values. We have presented the idea of personal accomplishments and suggested that the essential purpose of the service is to help people achieve personal and social integration in the least restricted environment possible.

### The value of different viewpoints

At present, providers and users generally only meet at the point of service delivery. In future we would expect the people served to be more closely involved in the structures which decide, plan and support the process of service delivery (the provider system). In any event, a responsible provider system will take account of different views and be particularly interested in listening to those of the user.

The implementation of community care requires a particular and possibly radical new approach from service providers. Deliberate moves towards opening up the provider system to accommodate the variety of individual views of users will increase the likelihood of developing services that are needed and wanted, as well as helping to carry all participants through the difficult process of change. Consideration of what may then arise as legitimate planning concerns would also show we respect and value the user's contribution.

### A shared vision

In addition to noting the individuality and variety of users, we have also to take account of the disparate nature of the provider system itself and the tensions within and between professional, administrative and political concerns. It is our hope that the process of clarifying the aims and objectives of a mental health service will help unite participants and create a shared vision of a future service based on fundamental human values. Normalisation in this sense is an ideal which poses a constant challenge for service providers. Meeting these challenges and understanding the compromises and trade-offs is an essential function of a responsive, dynamic service. Thus, normalisation provides a working philosophy that informs service goals, generates values underpinning the planning and development of services and serves to stimulate new ways of reaching local objectives.

## Preparing for the management of change

Community care is about the management of change on a grand scale. It is not simply about dealing with marginal changes within a well developed service structure but fundamentally redesigning interdependent care and support systems. It will impact considerably on external systems and it follows there can be little certainty as to the eventual outcome.

Everyone will have doubts. At strategic decision-making levels there are presentational, political and financial pressures with which to contend. At the point of service delivery, the reasons for change may be taken as implied criticism of professional competence and practice. Users, relatives and indeed the general public may be no less alarmed by the prospect of change. It will be necessary to consider everyone and everything affected during the design, implementation and development stages of the plans for the new service.

The task is to create a culture, a climate of acceptance for the change, to communicate a vision of the new service and to encourage people to contribute to its realisation. Senior management will need to support those who are receptive to change, reassure those who are uncertain, prevent hardening of attitudes and deal with any entrenched interests in a constructive manner.

## Planning valued services

The message for planning purposes is essentially a reiteration of O'Brien and Tyne's statement:(1)

> **'...normalisation is not something which is done to a person; it is a principle for designing and delivering the services a person needs.'**

A better service is designed by:

- stating the principles underlying the process of development from the initial recognition of need;
- formulation of ideas to meet those needs;
- consultation with others in the system;
- reformulation in the light of comments;
- gaining support, approval and finance for the plan;
- refinement in the light of experience.

Everyone should be concerned to ensure that the information necessary to implement various stages of the plan passes undistorted through the system, and that a clear picture of progress is also communicated. As the plan unfolds, feedback from the point of delivery will be essential so that management can respond appropriately to changing needs and circumstances.

Plans are not tablets of stone. At present, they are discussed with all sorts of people but rarely those for whom the service is designed. Once finance is allocated to specific schemes within the plan it is often difficult to change them. Yet this is precisely what ought to happen if better ways can be found to achieve the service aims, or subsequently if it appears that the original design is neither wanted nor needed by service users.

Initial plans for change on a grand scale should not be allowed to dictate the ultimate direction the service takes. It is better if plans remain flexible to incorporate experience gained during implementation. The importance of stated principles and goals becomes further apparent as a means of testing variation to the original design.

The need for a 'total resource' approach to planning emphasised in the DHSS draft circular(2) on the role of joint consultative committees (JCCs) in joint planning should help to bring fresh perspectives and new partnerships with those traditionally excluded from the planning process. Managers of current statutory and voluntary services will need to find out just what resources are available and agree how these can best be coordinated and deployed. They will need to pool their knowledge, exercise imagination and look at familiar resources and local problems from different perspectives. They will need courage to loosen their control over the direction services take. In practice, commitment will be fostered by encouraging staff and the people they serve to participate in planning and implementing the new service. This is not to deny a place for firm leadership but rather to suggest that leadership must be inspiring.

## Working together for a radical change

Experience shows just how difficult it is to implement change. What has been suggested here is that the changing nature of the service will itself be a force for changing the way the service is organised and produced. The days of a single service defining and directly providing everything a person needs are surely over. In many instances what needs changing is our perspective on what is appropriate for a mental health service to provide directly and what that service ensures others provide. For example, ordinary people enjoy access to a variety of desirable services. There is no reason why a community care service should not aim to ensure similar access to the people it serves.

Among other things, community care obliges local and health authorities to work together to consider their respective institutional boundaries. It obliges care disciplines to re-evaluate their roles and training. It obliges staff and users to consider their future and government to consider the strategic implications, costs and funding mechanisms. It must be appreciated that a sense of force or obligation usually only achieves compliance and rarely produces a corresponding change in attitude. It will be a difficult task to ensure that the anxiety raised by the need for change does not harden attitudes against change. In later chapters we address these issues more closely, but the point underlines the need for cooperation between all those affected by the change.

## Involving other agencies in management

The reorganisation of a large hospital-based service to the much smaller scale of local communities will also pose many difficult questions concerning personnel policies, managerial style and funding mechanisms, especially in joint projects employing multidisciplinary teams. Although many such projects are working successfully, we do not yet have sufficient experience to promote any particular management/employer structural model. Perhaps it would be helpful to distinguish different levels of strategic and operational management: the former is concerned with overall objectives and accountability, advance planning and financial arrangements; the latter with more day-to-day budget and service management matters.

Given that one of the main individual care work tasks will be to help coordinate the different services a person needs, it follows that management would be helped by interagency representation and advice. If multidisciplinary team work has been difficult in the past, how much was due to problems with external resource allocation, lack of support from organisational hierarchies and the absence of structural and operational links with other agencies? In many service areas, some form of interagency management is likely to be the most appropriate and practical way to approach common problems and ensure coordination of service provision. Such an approach need not preclude or deny management responsibility to individual service managers. In fact, it may well encourage it. Effective teamwork usually requires clear and well supported leadership.

This approach can often be found in the new task oriented local voluntary agencies which are set up as a means of bringing together service providers, additional resources and specific expertise. For example, several London authorities are setting up consortia of local housing, health, social services and voluntary agencies within the framework of charitable companies limited by guarantee. Their constitutions can provide for equal partnership through representative nominees of the constituent member organisations. Although the principal aim is the finance, development and subsequent management of housing, the provision of care and related support can also be arranged and coordinated either directly by the consortium or through the respective constituent members. The ability of nominees to take decisions on behalf of their organisations will no doubt be crucial to the success of the joint enterprise. Careful consideration must also be given to their representative structure and accountability, particularly as regards the participation of tenant representatives.

Consortia such as these will be useful for gaining experience of joint working but they will not be the only answer to structural problems of partnership in service provision. Over the next few years it is expected that several innovative models of joint care and management will be tested with a great deal of interest and scrutiny. It may be tempting to follow the route of a single service management employer. Such a simplistic approach would ignore the current reality of a diversity of practical experience and legitimate claims to the provision of community services. The creation of a new community mental health worker profession has also been suggested.(3) Whatever finally emerges, it is hoped we do not limit the variety of services available, nor reduce the opportunities for choice for service users. What must be argued is that service boundaries should be loosened and services coordinated within a common philosophy. Improved interagency communication and different professional perspectives working within a coherent approach will yield a rich and variegated, more responsive local service.

## Small scale service facilities

We are moving, it is hoped, from a buildings based service to a network of human services. Yet we must still consider new ways of providing housing and day care facilities. In this paper we promote the use of small scale housing for accommodation needs. The crux of the problem of buildings is the way they are used, whether they promote integration or institutionalisation and restriction. It can be argued that no building inherently promotes institutionalisation, but the larger the building, the more people living there, the greater the degree of internal organisational control that is required. There is less flexibility and allowance for individual differences. A ward or hostel of 24 people will generally tend to be seen to function as a homogeneous unit. In contrast, a range of 1-4 bed flats and houses can still be managed as a 'unit', but allows for a great deal of individual difference, expression of personal style, choice and location preferences. It will also encourage a more individual approach from direct care staff.

The initial problem of accommodation will be to find out what those individual choices are likely to be so that at the outset planners can be reassured they are heading in the right direction. Buildings often take several years to develop. The question of how, for example, to reconcile the need for advance planning for a hospital closure with the need for in-depth assessment and discovery of individual preferences will be considered more fully in the following chapters.

## Project-based approach to service implementation

As it is likely that the introduction of community care in particular districts will be phased over several years, a project-based approach is favoured. Moreover, experience of introducing projects to resettle people from long-stay hospitals is growing rapidly. Although the nature, range and scope of services and facilities developed varies considerably, several commonalities are emerging in these early projects, one of the most prominent being delays in implementation.(4)

The main advantage of this approach is that local experience of developing new projects can be used to assist the implementation of future projects. Put crudely, the pioneering, trail-blazing project prepares and marks out both a practical and psychological path for subsequent projects. The negotiation of access to people living on hospital wards, deciding who will move to new facilities, developing new care delivery and management systems, scheduling capital and revenue funding and the general acceptance of community projects, should all be easier the second time around. There may still be problems - the recruitment, redeployment, training and retention of staff, and delays in building and adaptation programmes, obtaining planning consents and arranging adequate long-term finance - but at least a more realistic appraisal of the development process can be incorporated into future implementation plans.

Certainly these pioneering projects are highlighting inadequacies in the system as a whole and it is beyond the scope here to review the many reports and literature on the subject. However, a general observation can be made that the longer people wait for a higher authority to resolve their difficulties, the less likely it is that community care will be implemented successfully. For, despite the patchiness of implementation nationally, it is becoming clear that where there is local commitment to change, these difficulties can largely be overcome.

## The practice of principles

As stated, normalisation does not provide ready made solutions to the problems of planning and introducing new services, but it is a guide and reference for their consideration. For the care worker, learning about and using the principle will be challenging - a continuous process of evaluating different situations and strategies for individual care. Very often it will suggest alternatives and highlight dilemmas to be resolved. It will be a central activity which must be shared with colleagues, managers and service users alike. Using the principle may ultimately be the only guarantee of appropriateness and quality in the service provided. Whether the consequences of a particular care decision are acceptable to the individual concerned, and how far these go towards meeting the accomplishments outlined in the first chapter, will be a prime responsibility for everyone working towards the provision of personal care.

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# CHAPTER 3

## THE DEVELOPMENT OF A COMMUNITY SERVICE

One may be forgiven for thinking that the implementation of a community-based mental health service is a dreadfully slow process. The policy is more than 30 years old. Time enough to have sorted out the fundamental issues of structural change, to have developed the range of community services and facilities people need and to have reduced, if not eliminated, reliance on long-stay hospital provision. Yet despite general acceptance of the ideas of community care and evidence that the pace of change is accelerating, the practice is notably patchy and woefully inadequate.

Due mainly to mortality among the 'old long-stay' hospital residents and the increased use of home-based drug treatments for those newly entering the psychiatric system, the decade since 1974 saw a 25 per cent reduction in hospital provision. Perversely, the same period saw hospital staff increase by more than 40 per cent(1) but little or no increase in community resources. A combination of economics, a change in the philosophy on care and in the patterns of need has led inevitably to a programme of closure for many of the large Victorian hospitals. But with insufficient community resources, difficulties with inter-agency planning, staffing and accountability, uncertainty about managerial responsibility for emerging services and insecurity about finance, particularly in the long term, it is no wonder that the Audit Commission found progress 'slow and uneven'.(2) It is also not surprising that among the current community projects, many have encountered antagonistic resistance from hospital staff concerned for their own future and the future of those they serve.

Against this background of uncertainty the development process necessarily continues. It is hoped the current strategic policy reviews of community care will help to clarify the framework of organisational structures and bring security and simplification to the financial mechanisms. Time is running out in the hospital closure programme and current community initiatives need to be reassured that they are heading in the right financial and managerial direction.

Since no one knows what the final framework of community services will be, perhaps we should concentrate on laying the foundations on firm principles. Without a firm foundation the eventual structure will collapse.

## A case study in development - design of a values-led service

Presented below is a case study in development of a community-based service. The projects described aim to help resettle a number of people who are long-term residents of an old Victorian hospital serving a number of district health authorities which is due to close in seven years. The projects are the first in the closure process. The study is about a hospital closure but the example could be applied to a situation where hospital provision is being reduced, or where a known group of residents would like to live a more ordinary life outside hospital.

The first section is a light-hearted yet serious look at some of the pertinent issues and ideas. It is presented as an informal and free-ranging discussion by some of the key stakeholders in the district which manages the hospital. They are struggling with newly acquired concepts but are committed to working together to design and implement a values-led service. The second section concentrates on implementing community projects.

### Discussing the idea of accomplishments

A special informal meeting of the mental health subcommittee of the local JCC was convened to discuss the hospital closure and was directed to assist health authority planners draw up specific proposals for further consideration. The meeting involved the planners, their local authority colleagues in housing and social services and representatives from local mental health voluntary organisations. They decided to ask themselves a number of questions about what they hoped to achieve for the hospital residents and the shape of the local service, based on the service goals and essential accomplishments stated in chapter 1. The questions and ideas raised by the subcommittee are given below.

## Community presence

Do we know this community, the different neighbourhoods and facilities? How familiar is this environment to hospital residents? How can we make it more familiar? Should people be given opportunities to get to know the community? Do people have friends and family there? How will individuals make friends, create and extend their social networks? If we are to achieve social integration, dispersal of facilities is important. We must avoid creating ghettoes which distinguish people as being different. How do we find out people's friendship patterns and location preferences? We'll have to get to know some of the people we're planning for and ask them. How can we reduce the community's anxieties about community care?

## Protection of rights and promotion of individual interests

Do we know whose or what rights we are going to protect? What rights do we have in the community? Does the community have rights and may these conflict with service users' rights? If so, whose side are we on? We must distinguish rights from expectations and should define user rights in this service. How do we involve the people served in this process? Could we encourage an advocacy scheme and user forum? What about individual potential? How can we encourage this while taking account of initial or continued vulnerability? Do we need to train staff in welfare rights? Are we going to encourage people to make use of local educational, recreational and social facilities or do we provide our own facilities? How about doing both? Should we incorporate a complaints procedure? Yes. And we must ensure people know what their options are. An advocacy service in the hospital would be very useful.

## Personal continuity

How do we ensure a sense of continuity between hospital and community? Do the present care staff move with residents known to them? (not without considerable further training).

It will be hard to break institutional attitudes. Perhaps continuity should be provided by future project staff. How do we ensure services are coordinated? Do we need individual support service coordinators? Bit of a mouthful. Why not case managers?

Sounds too derogatory; language is important. After moving to the community people will need someone to help them make use of community services and facilities. Let's have a principle of 'least moves' about the system in order to meet the person's needs. Good idea. I expect that will mean peripatetic care workers and some form of mobile support teams, crossing system/service boundaries. The care coordinator could also be a budget holder and provide feedback about services people need which have yet to be developed. That will help us too.

### Continuous personal development

Surely this means extending real choices, training and education to realise people's potential for growth. We must always assume growth is possible. What about risks: how far can we go and what safeguards do we have? It's ironic that we're talking about other people's growth and their taking risks and we don't even know them. We must plan for individual change and allow it when it happens. Risks are inevitable. There are no absolute safeguards. Shouldn't we start as we mean to go on - involve people in the decision-making process from the start and encourage interest in their personal direction? How do we do this - the user forum idea? People don't suddenly acquire these skills but they can be helped. Skills training in useful activities will be helpful. Who does this - adult education, the hospital rehabilitation department? Most of this effort should take place in the community where it is needed; skills are better learnt where they need to be reproduced. People's needs change, but obviously basic survival skills will be necessary before moving out of hospital. Depends where they go.

## Image enhancement

What are the valued options in life? How can we offer these? What can we do to show we respect people and how can we help develop their sense of self esteem? What will other people think about the former residents? Can we ensure there are realistic opportunities to reach respectable standards in housing, clothes and personal possessions? Can we ensure sufficient disposable income in order to maintain standards? We had better talk to a welfare rights expert quickly. The benefits system is hardly a valued option. We must do everything we can to extend the limits of what is available to provide the best possible service we can.

How about turning over the average care cost to them. £14,000 a year for life is fairly image enhancing. Yes, but part of that pays our salaries. So it does.

## Community participation

We won't really know about this until after people have moved out. It's the greatest challenge. Can we plan for it? We must consult with colleagues in community education and recreation services. That's not quite what it's about. It's something about evaluating what the service is achieving. Do the advocates play a role here? What about individual volunteer befrienders, valued members of the community whose role involves creating opportunities for those they befriend, to meet other people and take part in social activities? You can't rely on volunteers, though it might help if they were paid something. It's about developing and maintaining relationships in a variety of different settings. While we're all together can we begin to get some idea of what services already exist which are available to ordinary people which aren't stigmatising and which are positively valued?

## Design deliberations and discussion of strategy

A lot of these accomplishments have common elements. Perhaps we should extract these as our proposed service aims, principles and operational goals. A programme of public education will be useful so that people can begin to appreciate the changes being made and comment on them. This could be linked to the consultation process. We are already beginning to get some idea of what the new service will look like and how to go about its implementation. Have we got enough to start with?

## Valued living arrangements

As far as services go we have possibly got enough to start, but where are people going to live? We should start by considering the range of housing options open to the community at large. What is valued? A home of one's own in a good area; nicely furnished to one's choice; living alone or with others of one's choosing; near shops, public transport and other facilities; nice garden; bit of a view. But what about the fact that the majority of hospital residents have spent most of their adult lives being looked after 24 hours a day, with all meals provided and few financial pressures? How are they going to cope in ordinary housing? Some may never be able to cope by themselves, but the key will be appropriate and sufficient staff support. Whether this support needs to live in or be available 24 hours a day remains to be discovered. Assume the least restrictive environment from the outset. We could investigate adult fostering schemes and a range of other options, including crisis accommodation for people having difficulty, some form of respite care and non-institutional asylum. We are not going to 'reprovide' the whole hospital at once and this gives us flexibility to assume that people can achieve more independence than might appear from consideration of the present arrangements. Clearly we need to find out what the residents need and would like and what they might be able to sustain given appropriate help, training and support. We must also ensure people have informed choice over their living arrangements.

**Initial plans and principles**

If we assume an initial range of provision, a small proportion of the eventual requirement, we should be able to find residents who would want and can be prepared to move out. Even better, we could get to know a representative cross-section of the residents, invite them to consider the options and develop accordingly. If people change their minds during the delay or if we subsequently find that more or less of a particular option is required, we can adjust our plans. Ordinary housing is very flexible. Of course, once a particular development has started, it is difficult to change midcourse, but that is our problem. In any event, the early stages give us the option of finding people who could make use of the initial range from among the whole hospital. This process will also allow us to refine our medium-term plans as well.

**Hospital staff consideration**

In addition to the residents, the views of hospital staff must be considered, particularly the consultants and ward staff. The change involves them too and it may be more difficult to get their support for the proposals than to persuade the residents the hospital must close. There will be worries about jobs and changes in working relationships. There will need to be a comprehensive personnel and training strategy. Normalisation is not just for service users; it is for staff too. The traditional hospital hierarchy will not easily adapt to community work. Practices will change dramatically and many will see the change to community care and focus on user needs as a threat to status and service traditions. Perhaps we could encourage the more influential staff to become involved in the initial training programmes. We must also consider the role of ancilliary staff in the new service.

## Housing matters

We must consider the finances and development of any new facilities, particularly housing. We have got our own property, but a lot of this is inappropriate, being too close to the hospital and already strongly associated with us. We must acquire housing in the community. We can draw on the expertise of local housing associations. They may even be able to raise extra capital resources and suggest ways of defraying housing revenue costs. It may be more appropriate if the association were the future landlords. The health service job is essentially to care for people, not to be property developers and rent collectors.

## Financial arrangements

As the hospital begins to run down there will be savings to be made. How are we going to manage the retrenchment? The hospital serves different districts and everyone will need to develop their own community facilities. We must ensure there is an equitable distribution of resources. How do we avoid argument about which resident goes where? Will the financial resources transfer with the resident? If so, on what basis? If each district agrees to take a demographically representative number of residents, we could transfer on the basis of average care costs. Each district will need to consider their own requirements for development bridging finance and no doubt there will be local variation and special circumstances to consider. This may mean local authority and voluntary sector projects negotiating with their respective health districts. It would be helpful to have a more neutral forum to do this. Perhaps other JCCs could play a role here. Do we know what the regional health authority is thinking on this?

## How do we coordinate access to the hospital?

This could be difficult. We cannot have several different project teams charging around the hospital recruiting the same residents to different schemes. It would be chaos. We could try sectorisation - allocating certain wards to particular districts. Of course, the problem here is that when residents begin to leave, some wards would become uneconomic. The hospital would be under pressure to consider moving people from ward to ward to achieve savings. This would be against the 'least moves' principle. Alternatively, we could restrict all project teams to a few wards at a time and ask them to coordinate their access with ward staff and residents, to minimise confusion and activity. Inevitably there will be disruption. A problem here is that people's friendships do not obligingly rest within ward boundaries. We could have just one hospital-based team which facilitates the assessment and selection to different projects, but it would not work without considerable liaison with project staff, who would in any event want to be involved in the process. Besides, we are not exactly selecting, but facilitating individual residents' choice.

### This way for a community service?

There was a lot to consider. At the end of this meeting the participants agreed to meet again with draft proposals for a common service philosophy. From this it was expected that different agencies would generate suggestions outlining respective contributions to the new service. One of the main tasks in the future would be to devise operational policies for liaison between agency service elements.

A full information and public consultation programme was to be devised with the help of a firm of marketing consultants. Each agency was to be responsible for internal staff consultations and finding ways of eliciting the views of service users. At each stage of the development process health and local authority members would necessarily be invited to contribute to and eventually approve the plans and strategy. In practice it was hoped this could be delegated to members of the JCC who would serve on a small number of essential coordinating committees.

**Voluntary sector**

Advocacy and befriending schemes need to be considered to help with establishing a user forum at the hospital. Small-scale housing could be developed with no resident staff but linked to a shop-front, drop-in facility. This would have an open door policy, functioning essentially as a social centre but with multidisciplinary mental health workers as care staff supporting housing residents on a peripatetic, 24-hour basis. Service users would be encouraged to run the centre activities, and other support services would link in to statutory resources. The employer would be a voluntary agency but statutory representatives and users would be expected to help its management committee.

**Housing associations**

A consortium of health, local authority and voluntary agencies would establish a new management agency for housing developed with finance from the health authority, housing corporation and building societies. The care staff were to be drawn mainly from the health authority, but the agency would also employ housing workers. It was calculated there would be surplus income to pay off the building society mortgage element of the capital finance.

**Local authority**

Social services proposed expansion of their day centre facilities and were prepared to offer office accommodation to community psychiatric nurses, psychologists and occupational therapists. Inter-agency mental health teams would be jointly managed with a joint budget controlled by individual care coordinators who would have links with all local service facilities. The housing department offered a small number of flats and houses, principally as 'move-on' accommodation if necessary. Other schemes included staffed hostels for people with dementia, adult fostering and the establishment of an emergency on-call service to support all unstaffed flats and houses at night and at weekends. Any private sector establishments would be urged to consider normalisation training of key staff when registered under the Registered Homes Act 1984. Community education and recreation services saw little problem in extending their services to future local residents. They already catered for a variety of interests and had long experience of helping people with special needs. A specific proposal involved domestic skills training in people's own accommodation.

**Health authority**

The health authority proposed a complete training programme for all staff in the mental health service, which would also be open to other agencies. A small number of acute facilities would offer short term asylum, hotel services and medical treatment. These would be separate from the multi-purpose service centres providing offices and resource facilities for all community staff, and would offer assessment, training and social facilities to local residents. Fifty per cent of the mental health budget was to be allocated to joint funded schemes or externally purchased services. The authority considered it would retain overall responsibility for the service budget and thus would be expanding its management services. There would be a key investment in an inter-agency management information system.

> **'Such stuff as dreams are made of ..?'** (A Midsummer Night's Dream)

## From hospital to community - a study of resettlement

### Assessing housing needs

One of the primary tasks in developing community-based services is clearly identifying and providing a range of housing options. There are a number of ways that this task can be undertaken.

Housing could be provided directly according to need. This would necessitate an assessment of the people leaving hospital and moving into the district. Given that it takes some time for resettlement workers to get to know individuals, and to help them reach an informed choice on housing, this approach may not prove feasible. For workers to obtain information on housing from all people returning to a district would probably require two to three years.

An alternative approach is to make assumptions about the necessary range of housing. Tower Hamlets Mental Health and Housing Working Party(3) undertook a survey of need for accommodation and support services for a representative sample of people who were long-term users of the mental health services. They compiled a register of long-stay inpatients, frequent admissions, clinic and day centre attenders. They also gathered information through questionaires completed by staff, interviews with users and staff, and compiled a scale measuring dependence, activity, effects of current symptoms and degree of isolation/inactivity. The survey yielded valuable information and enabled the working party to predict fairly accurately accommodation needs for the entire district.

This type of survey could be adapted for use with people in hospital. Equally, getting to know a sample of service users in depth may provide sufficient information to predict overall housing needs. Hospital assessment methods are also useful measures, but the resettlement workers should be wary of relying only on hospital-based information. Staff from wards designated for closure may not be the most appropriate people to do individual assessments. To ensure a fresh look at each person, unaffected by preconceptions of their ability, a new group of staff should be the ones to coordinate individual assessments and to make predictions on housing needs. In practice this will most probably be the resettlement or contact team (see below).

Whatever the predictions of housing needs, a range of options will need to to be made available. These will range from staffed homes, multi-occupancy homes, single flats, adult fostering, respite care provision, and so on. Clearly liaison with the local authority, housing associations or voluntary organisations is essential at the earliest planning stages. It must be remembered that other districts will be developing housing as well. This may mean that access to the hospital for initial assessments is limited. It may equally mean that numbers in a specific project may change over time as people are resettled with their friends in the hospital. Housing is discussed in more detail in chapter 6.

### Crisis services and respite facilities

The need for support in crisis, and the provision of non-institutional asylum are mentioned below. Crisis services and respite care facilities will have to be established in time for the first discharges from hospitals. This will be a time of high stress and anxiety for people, and skilled, sensitive support is necessary to ensure they do not end up in a psychiatric admission ward.

In shared living arrangements people do not always get on with each other and it may be that alternative arrangements will have to be made within a few months following discharge. The use of admission wards in such circumstances would be entirely inappropriate. Temporary alternative accommodation pending a more long-term solution may be essential to prevent a drama becoming a crisis that consumes staff resources and causes considerable distress to those involved. Such a facility may help to prevent the demoralisation that can occur if a person or placement appears to have failed.

Obviously the contact team will be working hard with people during these first months, but other specialist crisis services should be available. Indeed, crisis teams will form an integral part of a community-based service.

## Resettlement work in hospital

### Strategies for change

A decision to close a hospital is a commitment to carry through a complete move of all patients. An incremental approach will be useful, allowing experience gained to help refine community service plans. At first there may be few staff who can be devoted to the exercise; activities should therefore be limited to a small number of wards. Initially it may be necessary to identify people prepared to move to facilities already in development. Within a short while it should be possible to develop service options for people based on more explicit knowledge of their needs and wishes.

Housing and other facilities often take a long time to develop and staff should be wary of an unacceptable delay between availability and active preparation for discharge. To avoid losing momentum and interest, individuals should not need to make firm decisions about service facilities more than a year before they move. However, people should be able to consider the options and their future for longer than this.

### The 'least moves' principle

As a general rule it would seem most useful to observe the 'least moves' principle. People should not have to move from ward to ward prior to community discharge; they should be able to move directly to their most desired living environment. Also, if social networks are taken into account within the hospital, it may be that some people will want to live with friends who are not resident on designated closure wards. Bed spaces may thus become available in the short term on wards not immediately closing for people not yet ready to make a decision to move out.

### Social networks

Often those with mental health difficulties have problems holding onto or developing their social networks. People who have lived in a psychiatric hospital for a long time will have particular difficulties moving into the community unless staff recognise the importance of people's existing social networks in the hospital. Friendships, of course, can make planning difficult as they do not respect ward boundaries, ages or disabilities. However, if two friends would like to live together, who are we to deny this? In chapter 7 we will look at developing social networks in the community.

## The work of contact teams

Project contact teams could be given the task of identifying individuals and finding out what additional resources and services are needed. This information should be relayed to service providers. It is probably better if contact teams are mainly comprised of resettlement staff who can provide continuity between hospital and community. A major part of their role will be to help people prepare for a new life and to give continued support in the community. Whether team members are drawn from a number of different agencies or are specially recruited will depend on local considerations. However, it is suggested that teams will require coordination and leadership from someone who can relate to and be supported by existing agency hierarchies.

The first step might be to establish a presence on the chosen ward and get people used to the idea of change. In this situation experience (for example, MIND in Waltham Forest) suggests that each member of a contact team can eventually manage an active workload of three to six people depending on the range of needs. Following a decision to move, someone may need full-time attention for at least three months prior to discharge. A multidisciplinary team of six with no other duties, gathering information directly from the people themselves, explaining their work and helping to prepare individuals for discharge, should be able to start resettling a ward four to six months from first contact. They should help close it completely about 18 months thereafter - provided housing and support services become available.

The key factors affecting the way contact teams organise their work are the number of staff and wards involved, the time scale and the objectives. An example range of ordinary housing has, let us say, 15 units with a total of 30 bed spaces. Sufficient housing for five people is planned to become available at three monthly intervals allowing serial resettlement. In theory, once the first houses are ready, the contact team of six have eighteen months to resettle 30 people, splitting their time between hospital and community. In practice the development process is uncertain, with some buildings delayed and others brought forward. Once houses are ready to hand over they must usually be settled quickly to meet charges for rent and so on. These uncertainties put pressure on all involved. Few hard promises can be given and team plans will have to remain flexible.

Furthermore, as houses are resettled more staff will be needed for support. Following the principle of continuity of care, our model would suggest contact team members start developing individual plans in hospital and become the care coordinators in the new service, working directly with other care workers and the people resettled. How many other care workers are needed will depend on a range of factors peculiar to the project in question. In this example at least a further six will be needed. Managers should be able to respond quickly to the need to bring in extra staff as necessary.

Service contact teams must initially spend time with ward staff, getting to know their routines and views and beginning to understand the context and environment people live and work in. Both staff and patients are likely to be uncertain about the outcome of events and to experience periods of difficulty and anxiety. A natural consequence may be to question the need for change and to resist its implementation. Managers will have to be alert to such resistance and give extra support when necessary.

The response of hospital staff may well be crucial to the success of the exercise. It is management's job to ensure they are prepared to facilitate the work of contact teams. Introducing the ideas of normalisation on to the wards, or a simple general ward programme aimed at increasing self care, would help to prepare people. At the same time it would give staff a positive role in the closure programme. Ward staff will find that their daily routine changes, leading to new and different goals. Contact teams will need to discuss with staff the best way of working together to meet common desired objectives. But, it is hoped, both groups of staff will support the other through these new experiences.

**Developing forums**

It may be useful, particularly when contact teams from different facilities are working on the same ward, to set up a forum for exchanging information on a regular basis. This forum should be established as soon as contact teams start negotiating access to the wards. Indeed such negotiation would take place through that forum. A service providers' forum would include hospital staff, the resettlement team, management and other interested parties such as voluntary organisations and users. It should have floating membership reflecting the need to involve different people in the different stages of identification, assessment and preparation of people for transfer to new facilities. It should include unit management team representatives to help solve problems as they arise and to assist in coordinating the closure programme. Furthermore, there are lessons to be learned which must be relayed to the joint planning team.

User only forums could be developed, initially perhaps with staff support. The aim would be to enable users to discuss the changes, give their opinions on plans presented to them and to elect representatives to work on planning teams, service providers forums, and so on.

### Getting going

The transfer programme could be presented at meetings of the whole ward, attended by the contact team, residents, ward staff and so on. Individual members of the contact team could work shifts alongside hospital ward staff as observers; this would give everyone a chance to get used to the new situation. Before long the contact team would want to start working with individuals in order to get to know them. Trips out of the ward or out of the hospital to the sites of new facilities, visits to local pubs and social events should all be encouraged where appropriate.

A major task will be to explain to people what is going on and to get them to appreciate the options before them. It is a good opportunity for them to exercise choice, but at this stage an individual may be apprehensive, uncertain and not able to accept the situation. This may reasonably lead to a decision to stay put and this choice must be respected. In the short term it may be possible to accommodate that wish but, of course, it would be impractical in the long term.

### Choices, risks and the problem of institutionalisation

Choices should be extended to people at every opportunity with support and gentle encouragement. No one should be forced into accepting a service option nor left in ignorance of what is available. People should be able freely to choose their future. They have a right to be informed and given realistic choices.

Informed choice is being able to visit prospective placement facilities and knowing what sort of services are available or additionally needed. It is imagining what life may be like and it often requires help from others to identify needs, together with a gradual working on skills and abilities to demonstrate new possibilities. We will see in chapter 4 how Lambeth MIND is tackling this problem.

The institutionalisation and dependence on the routines of large hospitals, the many years of drug induced damage and the conditioned acquiescence to control by others, is a tragic waste of human potential. Hitherto someone entering the present psychiatric system stood a good chance of becoming little more than a passive recipient of care, dependent on a system which consistently failed to recognise their uniqueness and individuality. It is going to be difficult for many to exercise the choices available to them and control their own lives, yet we must consciously and consistently create those opportunities.

Hospital staff can facilitate the work of contact teams by de-institutionalising the routine as much as is possible. This would require staff looking carefully at the daily work routine to see if there is any way, however small, that the individual can take over a task performed by staff. For example, if drinks are served at regular times, could a kettle be provided for people to make drinks when they want one? It is the 'trivial' things, as well as major things, that cause institutionalisation.

## From patients to people - moving out of hospital

### Individual preparation

People differ in their capacity to make changes and in the amount and duration of preparation necessary to enable moving to a new environment with some confidence. Clearly someone who has gone through a well-designed, traditional, rehabilitation programme will be better prepared for community living than someone who has not. In the context of a hospital closure and limited rehabilitation resources this may not be feasible. It may then be left to contact teams to plan resettlement programmes with as much help from hospital staff as can be negotiated.

## Formulating care plans and involving others

The 'getting to know you' process introduced here is one approach to developing relationships between individual and resettlement worker. The process also ideally lends itself to the development of individual plans (IPs). These are both described in more detail in chapter 5, but in brief an IP is a statement of care and support strategies. IPs should include attainable goals which will, for example, gradually increase confidence, self esteem and a sense of life control. As a working document it will reflect all relevant views and be reviewed regularly. It must also be freely agreed with the person to whom it relates.

Work on the IP should begin in the hospital, but here the tasks and goals are more specific and focused on the short term. But the situation quickly changes in the months following resettlement and one can better appreciate longer term individual support needs. IPs should then be at the heart of a project's continued service development.

It may be useful, before someone moves and well before formulation of the care plan, to introduce advocates who can befriend and support the person concerned, arguing on their behalf if necessary. Advocates who are not responsible to the contact teams may also assist with preparatory work such as accompanying people out of hospital on shopping trips. However, their relationship to resettlement staff must be carefully considered, for the future care staff will need to assess people's needs and abilities in as many different contexts as possible, preferably outside the hospital. Also, it is likely that other care staff will need to become directly involved with the process of transfer to new facilities in order to supplement the teams which are dividing their time between hospital and community.

## Managing the resettlement programme

With such an intense build up to the day of the move, the actual transfer may come with some relief. It will be a tremendous achievement for all concerned even if one realises that the 'real' work is about to begin. The need for designated, individual care coordinators at an early stage in the resettlement process should by now be apparent. It is one of their primary tasks to ensure that preparation, formulation of an IP and physical resettlement is managed as smoothly as possible and within a tolerable level of anxiety for the person resettled.

Although care coordinators carry considerable operational responsibility they should in turn be well supported within a clear management structure which has good and effective links with hospital and other agency managements involved. The potential for pressure from differences of opinion, practical problems and professional issues is considerable and can swiftly lead to damaging consequences. It must not fall to operational staff alone to resolve such matters.

## Resettlement in practice

A summary of the resettlement programme devised by MIND in Waltham Forest appears below. From the initial contact with ward staff it was in fact eight months before the first house (2x2 bed flats) was resettled and a further 15 months before 13 people were resettled in four houses. The initial contact team of three grew to become a direct care team of six. Clients have an average age of 55 ranging from 35 to 68 and between them an average 27 years of contact with psychiatric services, mostly in institutional care. Staff do not live in the houses.

Firm decisions about household composition were not made until three months before a move and this subsequently was considered an absolute minimum in which to get to know, formally assess and help prepare people for moving. Some people were quite definite about with whom they wished to share; others needed help with deciding the household composition.

For all concerned, relationships were developed mostly through practical tasks such as cooking, choosing furniture and house colour schemes and generally finding out about the local area. Although skills were acquired and practised before the move, the period was characteristically one of psychological preparation. The most effective learning situtation was held to be the new environment which is where staff resources were most concentrated.

## Staff moving out of hospital

The use of external contact teams as agents of resettlement from hospitals and eventually as care coordinators or key workers in the new service will ensure continuity of care - albeit a different style of care in a different environment. It is probably best that hospital staff do not immediately move out with their residents. The step from 'patients to people' is an important one and staff will need time and training to adapt to new ways of working. However, given further training, ward staff who have seen their wards close in the way described above will have picked up enough information to assist in future ward closures and could thus soon slot into the new service. In the new network of human services in the community the only redundancies should be large, remote empty buildings and outmoded attitudes.

The table on pages 48 and 49 is a summary of a resettlement programme devised by the resettlement team of MIND in Waltham Forest.

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Assessment and Selection Process

| Stage 1 | Purpose of Stage | Information Required | Particular Methods Used | Role of Resettlement Team | Issues and Potential Difficulties |
|---|---|---|---|---|---|
| Informal observational stage to get to know the ward culture, and formal and informal rules. | 1) To establish a presence on the ward<br>2) Assess current patterns of ward activity, social interaction and group norms.<br>3) Identify areas of ward life/culture where a simple skills/independence training programme could be developed to maximise potential for change.<br>4) Establish projects credibility with ward staff to gain trust and cooperation for future work. | 1) Ward profile details<br>a) Number of people<br>b) Basic demographic details<br>c) Number of staff<br>2) Basic social networks<br>3) Profile of ward culture | 1) Participant observation as 'partial' members of the ward team working shifts with the staff. Three main areas not done by resettlement team:<br>a) administration of medication;<br>b) bathing;<br>c) restraining or becoming involved in 'violent' incidents.<br>2) Begin the 'getting to know you' process to build up a picture of 'life inside'. | 1) Disseminate information on resettlement process and projects coming on stream.<br>WITH STAFF<br>2) To establish project staff in 'non-judgmental roles' and to carry out practical tasks where appropriate.<br>WITH PATIENTS<br>3) To identify ourselves as 'non-hospital personnel' by:<br>a) not making assumptions re familiarity;<br>b) giving information re reprovision;<br>c) encouraging them to talk to us without prying or being over-inquisitive. | 1) Accountability while on the ward.<br>2) Team consensus approach to individuals.<br>3) Gender clarity; that is, works on male and female wards.<br>4) Problems of hostility; we are first on the ward. |
| Stage 2 | | | | | |
| Participating in ward activities, encouraging new initiatives and working with individuals who have expressed an interest. | 1) To encourage the development of relationships between project staff and patients.<br>2) To establish an environment of change to facilitate the process of adaptation.<br>3) To encourage the process of self-selection. | 1) More detailed information on social networks of people who have expressed an interest or are self-selected, both inside and outside hospital.<br>2) Assessment of individuals:<br>a) motivation;<br>b) ability to tolerate the stress of change; | 1) Developing simple ward skills programme with staff.<br>2) Outings to try to get people from different wards together.<br>3) Outings with individuals who had self-selected to the houses and the areas.<br>4) Preparatory skills | 1) To ensure that the purpose of the process is known to staff; that is, non-judgmental and not selecting people.<br>2) Ensure that failure labels are not attached to people who do not self select.<br>3) Clarify with potential project clients the service we | 1) Disagreements over suitability of people who have self selected.<br>2) Other projects coming on the wards.<br>3) Sex mixes of houses.<br>4) Project/ward personality clashes on different wards. |

| | | | | | |
|---|---|---|---|---|---|
| | | c) basic level of safety functioning (survival skills).<br>3) Looking at compatibility within/across wards to identify possible sharers.<br>4) Detailed information on individuals when they have self-selected using different data source (with individual's permission). | sessions with individuals and potential sharers.<br>5) Detailed 'home building' with people for the first houses. Choice of furniture and so on. | are providing, the expectations which they have of us and us of them. | |
| Stage 3 | | | | | |
| Individual care planning to prepare individual to move and exist in the community. | 1) To develop an individual plan for people moving into the project.<br>2) To build up survival strategies for people in the initial period.<br>3) To utilise available resources.<br>4) To stimulate ward activity. | 1) An individual social skills and functioning profile.<br>2) An individual likes/dislikes, wants to do/does not want to do profile.<br>3) Community profile to catalogue resources which include:<br>a) adult education:<br>b) womens centre;<br>c) leisure facilities;<br>d) GPs:<br>e) transport;<br>4) data for hospital procedure checklist. | 1) Use the 'GTKY' approach of 'what would it take to allow this individual to...'<br>2) Work with individuals and sharers on practical skills achievement.<br>4) Develop relationships which can be used during the transitional period.<br>5) Coordinate input with other professionals.<br>6) Get people away together for a few days prior to moving. | 1) To disengage from overall ward activities while promoting their continuation.<br>2) To draw up plans/contracts with individuals re programme planning, outlining expectations/obligations on either side.<br>3) To carry through the clinical work and also the liaison/admin functions involved. | 1) Monitoring and evaluation.<br>2) Identifying individual service coordinators.<br>3) Dependency issues.<br>4) Moving out and a sense of loss. Making sure of a positive 'good-bye'.<br>5) Implications of lower profile for others who may be in the process of self-selection.<br>6) Ward staff pressure on people to 'self-select'. |

(from Morgan and others, 1985).

has since become independent with its own constitution and identity. The group is currently proposing a tripartite scheme with the following components:

Patients' Councils

These councils will function like 'tenants associations' and will aim to increase service accountability to users, and promote the notion of care being a partnership, albeit an unequal one, between staff and user.

Paid Advocates

The advocate will work in a psychiatric hospital, while being independent of it in terms of responsibility and accountability (this will be to an independent management committee). They will offer welfare and legal advice, assist people in making complaints, liaise with patients' councils and so on.

Citizen Advocacy Coordinator

For those very disabled by institutionalisation, drugs or distress, then a model of citizen advocacy may be most appropriate. A coordinator would recruit and train volunteers to become advocates through a longterm relationship with a particular individual.

### Other advocacy schemes

The Sheffield Advocacy Project and Advocacy Alliance are well-established schemes facilitating citizen advocacy for people with learning disabilities. There are also some excellent examples of advice centres in psychiatric hospitals that offer legal and welfare advice to people and will, in some cases, represent them on mental health review tribunals. Mapperley Advice Project at Mapperley Hospital, and the Legal Advice and Representation Project at Springfield Hospital are two such examples.

### Mental Health Services Project, North Derbyshire

This local authority day centre, established in 1982, provides a service informed by the principle of normalisation. The starting point of the service was to provide a social support system that attempted to tackle peoples' real needs such as companionship, a nice place to live, employment, and so on. Their principles state that each individual should be given the maximum opportunity to exercise power and control over their own lives, and that relationships between people responsible for providing the service and people who use it are based upon skills and ability not ascribed status. There is a user-only only committee which is fully involved in all decisions affecting the centre and is responsible for out-of-hours opening and activities. The centre makes a genuine attempt to be fully democratic in its day-to-day running and local planning.

**The Camden Mental Health Consortium**

The consortium started in 1984 following an initiative by the local community health council who were concerned at the plans for mental health services being made by the health authority. The consortium consists of users, representatives from voluntary organisations and interested staff. Its aim is to inform the planners of the users' views and to be involved and proactive in the planning process.

**Survivors Speak Out**

This is an umbrella group drawing support from self-advocacy groups in the mental health field. It has two major objectives:

1 Improving communication between existing groups in this country.

2 Raising funds and organising a national conference of service users and workers. (The first conference was held in September 1987.)

People attend SSO meetings as individuals not as delegates or representatives of groups. The result of such contact has been an awareness of solidarity based on shared experience and of the range of possibilities opening up for individual advocates and self-advocacy groups.

# CHAPTER 4

## WHY IS INVOLVING PEOPLE AN ISSUE?

The movement towards involving people who use services in their planning and development has been prompted first of all by the realisation that a service cannot be efficient without some measure of consultation with, and involvement by, the users. Second, there has been a growing demand by users for an active role, and for a degree of respect and a new status within society as a whole. Their participation and involvement provides valuable information and ideas and may uncover previously untapped human resources. It is also an affirmation of democracy and faith in people, and may lead to users feeling less alienated.

### Quality services through user involvement

In the post-Griffiths era of management, quality assurance in mental health services has been highlighted and promoted. There are many factors to consider when pursuing and assessing quality, and many reasons why users should be involved.

The ethos of consumerism borrowed from industry and promoted by Griffiths has helped to focus attention on 'consumer satisfaction'. No manager in industry would sell a product without taking this notion into account, and there is a growing sense of services being judged by similar criteria. A powerful reason for involving users in this process is that they are the most significant stakeholders in the system, and have most to gain from a high quality mental health service.(1) A service, then, needs to ensure that the views of its users are adequately represented at every stage of the planning process. It needs to remain responsive and sensitive to information and opinions that travel up and down its communication channels. Unless notice is taken of users' opinions their representation will be merely a token and will have no effect on any real change.

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This chapter has been jointly written with **Peter Campbell** from Camden Mental Health Consortium.

The importance of user involvement in planning has been noted above. Equally, users have an essential contribution to make to the evaluation of services. Data, such as admission and discharge rates, are a measure of quantity and do not necessarily reflect the quality of services being offered. The quality of services can only be assessed through the experience of people receiving them; evaluations should therefore look at the impact of services on people's lives and what is actually accomplished for those who use them. The importance of the accomplishments defined by O'Brien in chapter 1 becomes paramount in assessing services in this way. There have been initiatives, by services, users and the government, to involve people in different ways in mental health services and examples are presented at the end of this chapter.

## Government initiatives

The following legislation is of crucial importance and goes some way to formalise user representation and participation:

### a. Tom Clark's Disabled Persons (Services, Consultation and Representation) Act 1986

The main provisions of the Act include clauses on representation and assessment. People with disabilities can now appoint representatives when dealing with social services; the Secretary of State can extend this to local health authority services. The representative can have access to meetings and information, unless it is deemed harmful to the person with the disability, and they may visit the person in the residential accommodation at any reasonable time.

(Clause 1) The assessment procedure allows the person with a disability, or a representative, to say why they should have services, and obliges the authority to give a written statement of their proposals, including their reasons for not providing services.

(Clause 2) Where a person has received inpatient treatment for a mental disorder for a continuous period of six months, the hospital must arrange an assessment in conjunction with social services prior to discharge. This covers people in mental handicap and psychiatric hospitals (Clause 4).

Other provisions in the Act require the local authority to provide information to disabled people not only of its own services under section 29 of the National Assistance Act (as now), but also of other relevant services which it or other organisations provide (Clause 6). Also, advisory committees set up by statute and required to coopt someone with special knowledge of disability must now consult organisations of disabled people.

This Act is a major legislative step towards promoting self advocacy and citizen advocacy. Its effectiveness, though, may be reduced by the insertion, in Clause 1, of the restriction in representation if the person's best interests are deemed to be affected. Advocates and citizen advocates must ensure that a patronising and harmful 'professionals know best' attitude does not neutralise the potential force of this Act.

Also, of course, there is no requirement for a local authority to provide the services that are indicated after an assessment has been completed. However, the assessment procedure itself should lead to a comprehensive survey of what needs to be available. This highlighting of gaps in the service can inform planners and develop public awareness of what is being offered and what is needed. These moves by the government could prove to be significant advances for people, if taken up by the authorities in a positive manner.

### b. **The DHSS Draft Circular: Joint Planning and Collaboration (1986)**

The circular is an attempt to make fundamental changes in the way services of common concern to health, local authorities and voluntary organisations are planned, developed and monitored. Local JCCs are given an active and positive role in producing a joint strategic plan for the development of services for all main care groups. The JCC will have an officer support group called the joint care planning team (JCPT). The membership of this team has been widened to include voluntary organisations and service users.

The circular makes it quite clear that:

> **'... planning should be directed towards meeting the needs of individual patients and clients ... service providers, clients, their families and community representatives including those of ethnic minorities are to have the opportunity to make a contribution to planning ensuring the plans are seen by consumers ...'**

The recruitment of service users to planning teams is indeed a welcome step, but needs careful consideration by staff and users on how best to introduce them into such teams. Unfortunately the circular gives no advice on recruiting service users as members and, as yet, we have little experience to draw upon.

## Self-advocacy movement in the United Kingdom

Self-advocacy can be defined as a process in which groups or individuals speak or act on their own behalf in pursuit of their needs and interests. This does not necessarily mean that self-advocacy groups will wish to involve themselves in the existing psychiatric system by providing representatives on planning bodies or the JCPT. It may be that self-advocacy groups will view any involvement in, or cooption by, the system as inimical to their needs and interests. There is the potential problem of whether the desire of planners and providers for user representation on committees can be effectively connected to people living in the community who wish to be their own advocates.

In reality the term self-advocacy has been superimposed on a number of rather disparate groups whose structures and intentions are quite varied. Although in general terms self-advocacy groups in the United Kingdom are campaigning for the same things, it is important to recognise the differences between groups. For example, some groups are already connected with service provision. Others are solely campaigning or pressure groups and have avoided any involvement in providing services. While some groups are concentrating on local issues and winning a position in the planning process, others are campaigning nationally on specific issues such as the abolition of ECT, or facilities for help in withdrawing from major tranquilisers.

Such diversity will pose problems for any initiative towards a coherent system of involvement. Although the existing self-advocacy groups represent a genuine movement of service users interested in change, it is not yet clear whether they could become the framework for the representative system which the present government seems to propose.

If the self-advocacy movement is to develop, if it is to become in any way a national movement, it must have some form of funding. Self-advocacy does not appear spontaneously, particularly in a field of public health where there is little tradition of people speaking for themselves. At present many self-advocacy groups devote a large part of their energies to raising money. If the concept of self-advocacy is seen to be of any value, it is unrealistic to expect it to survive without practical and financial support. In this respect an immediate problem is the possible conflict between the expectations of potential funding bodies and those of self-advocacy groups. The crucial elements in the self-advocacy movement seem to be articulation of, and action around, the needs of users as they see them. Whether those with funding resources can reconcile themselves to the independent position of self-advocates remains to be seen. It cannot be assumed that what service users are really asking for is only a chance to join in the game. At present the other side are providing the players and the referees. There is a danger that the new recruits could be confined to the substitutes' bench. Once again the difference between the form of what is being offered and the substance of what is being demanded becomes a real issue.

## User representation

There is a difference between user representation and self-advocacy. Whereas some existing self-advovacy groups are seeking and providing representation on committees, giving the general views of many users and are aware of and concerned about the needs of all within the service user group, they make no claim to be directly representative of people not within their group. It is unlikely, for example, that a group of people living in the community would claim to represent or wish to be seen as representing the needs of those labelled as 'psychogeriatric' or 'long-stay inpatients'. At present self-advocacy groups have neither the intention nor, more significantly, the resources to be representative in this sense.

When considering the subject of user representation it is helpful to be aware that there is absolutely no structure or tradition of representation in the field of mental health. Furthermore, there is among many, if not most service users, a well-founded scepticism about the value of such representation. It is not only that there is very little to build upon in terms of structure; it is also that the good faith of those who operate the system and hold all the power is under question. Over the last two or three years the experience of user-activists who are trying to initiate change is that doors are mostly being opened with some reluctance. This is hardly the most encouraging climate in which to encourage participation. This is not to deny, however, the very real efforts of some projects and authorities to listen and act upon users' views.

Whatever the motives, it should also not be assumed that coopting representatives from voluntary organisations, local MIND associations or self-advocacy groups, even if they are all individual users or ex-users, will be sufficient to provide effective user representation. There is no existing structure through which people can collectively express their view, and until that facility is established and resourced within the community there seems little chance that genuine user representation can be established.(2)

For effective representation then, on joint planning teams, community health councils and regional and district health authorities, there must be patient councils in all psychiatric hospitals, user representatives on the executive and management committees of all day centres and hostels and user participation in the training of mental health workers. The only way that change will be made is if involvement starts from the bottom up. Representation without power can be offered from above and it is possible that the powerless, without experience of involvement in the system, will take the bait. To build upward from the basic units of the user's life - the ward, the hostel, the day centre - may of necessity be a slower process, but it provides the best chance that genuine representation and a tangible shift in power will occur.

## Citizen advocacy

People who have been in hospital for many years may lack the resources to be self-advocates due to the effects of institutionalisation. Citizen advocacy is the process whereby a volunteer represents someone with the aim of improving that person's quality of life, and ensuring that they receive their full rights and entitlements. Robert Sang(3) states that: 'The most important concept underlying advocacy is that advocates and the people they befriend are both valued people and equal partners, each with unique experiences, skills and interests to share.'

People wishing to be advocates need to feel they will benefit from developing a friendship with the person, and be responsible towards them with regard to meeting commitments. Advocates must realise their own limitations, especially how much time they can give, and must communicate this clearly. Advocates also need to be independent of the staff group caring for the person so that there is no divided loyalty.

## Staff as advocates

Staff may feel that they represent the best interests of service users; and indeed they do, but not exclusively. Other demands are made on them: other patients to care for, the orders of a doctor, nursing officer or other professional, and the restrictions of 'professional boundaries' (for example, a nurse may disagree with giving ECT but their job requires that they follow the doctor's prescription). Also, should a worker 'stick their neck out' he or she may be labelled a troublemaker or be victimised, however subtly, or made to feel they are letting their colleagues down.

This point was highlighted by Virginia Beardshaw.(4) Her report cited the difficulties individual staff face when trying to `blow the whistle', not only on acts of individual culpability and cruelty, but on widespread dehumanising practices, such as automatically sugaring everyone's tea. (A survey undertaken by NAHA in 1984 found that less than a quarter of health authorities had guidelines for handling such cases, leading them to publish their own guidelines in 1985.(5))

One of the most vital components of advocacy, stressed in many of the projects and schemes, is the notion of independence; independence, that is, of the system providing care services. Staff cannot provide services and truly advocate at the same time. It is not possible to be an objective critic of oneself. It would be like being the case for the prosecution and the case for the defence at the same trial. Citizen advocates, or paid advocates, may be funded by a statutory body, but their management must be by a seperate body. Equally, relatives may not be the most appropriate advocates. They may also have a stake in the service system and so cannot be independent of it.

Perhaps the most appropriate role for staff is that of 'honest broker'. This would mean staff working with people, and their advocates, to provide information and to help them use this knowledge in the most constructive way. As with other brokers, staff are ideally placed to liaise between the user and resource providers to get the 'best deal' for individuals.

This is a different role to that of an advocate in that staff function as neutral arbiters, and are not solely representing the individual's interests. The development of staff as 'brokers' would seem an effective use of their skills in a way that would enhance user's self-determination, not detract from it.

## Current schemes and projects

The following projects are included as examples of good practice. They are not presented as 'blueprints' for local initiatives; they are chosen as working demonstrations of advocacy, participation and representation.

### The Dutch model

Patients' councils

The client's movement in Holland provides a powerful example of change being initiated by users themselves. In 1970 the patients in a large psychiatric hospital formed their own committee to deal mainly with leisure activities; this idea was replicated in other hospitals. The groups began to consider wider issues concerned with management of the hospitals. Many staff were supportive of these developments, seeing them as a way to improve communication and services.

By 1975 the patients' councils held their first national meeting. In 1980 a national umbrella organisation was established to support councils and to lobby for legislative change.

It is hoped that a law will soon be passed requiring that each psychiatric hospital will have a patients' council with a defined organisational position in the hospital.(6) Barker and Peck(7) report that some of these councils have negotiated representation on hospital committees, access to records and power of veto and mandate over some management decisions.

Patients' advocates

The national foundation established by the councils in 1980 employs patients' advocates to work in psychiatric hospitals. Barker and Peck summarise the position of patients' advocates thus:

1 Advocates have three basic roles:

  a Assistance to patients with complaints (advocates always take the patient's viewpoint).

  b The provision of information to patients about their legal rights (these are complicated by the absence of any specific legislation and are based in the 1884 Lunacy Act, common law and jurisprudence).

  c Liaison with the patients' councils over structural issues raised by individual complainants. The provision of such information helps patients' councils highlight their priorities for discussion and action.

2 Advocates are employed by the foundation not by the hospitals. This is important in that their advocacy role inevitably leads them into conflict with professionals and occasionally management.

3 Advocates, with the patient's consent, have access to the patient's records and can share this information with the patient.

4 Advocate appointments can be (and have been) vetoed either initially or subsequent to employment by the patients' councils.

5 Advocates mostly take a legalistic view of their role. Out of twenty advocates currently employed six are lawyers, six are psychologists, five are other professionals and only three are ex-patients. The starting salary is equivalent to the top of the scale for a sister/charge nurse.

### The Clients' Union

The union was initially started in 1972 by parents dissatisfied with their children's psychiatric services. A national television programme stimulated ex-users to become involved and the union was passed into their control. The membership consists of a user/ex-user category, and a non-voting, non-user category. The union was responsible in the 1970s for the voluntary advocate scheme, the forerunner of the paid advocate system.

The union, while not involved in policy making as such, is responsible for maintaining a high-profile debate on mental health issues.

What has happened in Holland is a stimulus for people in Britain. However, it should not be seen as a ready-made plan which can be similarily orchestrated in this country. The changes in Holland happened through a process whereby users themselves gained confidence and became empowered. Advocacy cannot be 'given' by staff; it has to permeate upwards from grassroots level.

The following are examples of advocacy schemes currently operating in this country.

### The Nottingham Advocacy Group

This group developed out of a growing interest in advocacy from statutory and voluntary organisations, and users themselves. Nottingham MIND took the initiative to form an advocacy group, which

**Lambeth MIND**

Service planning seldom includes research on consumers' views. In Lambeth the need to engage consumers in the planning process has been acknowledged by the health authorities.

However, the development of effective user participation received a low priority. Lambeth MIND developed a method of achieving this consumer input.

Pilot work had indicated that the area of most concern to local users was housing. Lambeth MIND undertook the task of trying to ensure that the housing to be provided by three health authorities would reflect the wishes of local service users as far as possible. However, in the long term they also hoped that the methods developed could be used for collecting opinion on other aspects of service provision. The Housing Advisory Group was formed to guide the work of the project. All members of this group are users of local services. One of the major challenges for the group has been how to seek opinions and enable service users to make informed choices when they may have received little or no information on possible housing options.

The Advisory Group chose to develop a simple game which aimed to facilitate discussion on various aspects of housing. While this has been successful in producing the information required, it relies on people being willing and able to participate in groups. So as to involve others, an exercise was carried out using picture cards. This method helped build up a picture of individual wishes and the housing needs of those with severe disabilities.

The completed work will be used on long-stay wards by patients and nursing staff. It is hoped this will give users an idea of what is available in an accessible format, and also provide an opportunity for patients and staff to discuss some of the issues relevant to their move into the community.

These are a few examples of many projects and schemes currently in operation. The variety of approaches reflects a multiplicity of usages and understanding of the term advocacy; there is a danger, of course, of there being a dilution or perversion of the notion. Care must be taken to ensure it retains its force for real change, and does not become confused with merely 'providing a better service' or 'talking more to clients'.

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# CHAPTER 5

## PLANNING FOR PEOPLE

New values suggest new ways of doing things. This chapter is therefore concerned with methods of planning for individuals which incorporate some of the aims of mental health services outlined earlier.

* Building relationships with individuals on long-stay wards is a way of finding out how they see their needs. Valued people have some control over their living arrangements and what they do with their time. It needs to be recognised that people living in long-stay hospitals also have a valuable contribution to make to decisions about where and how they live. They may need support in making their views heard but the result can be a fresh look at what services are needed.

* In order to meet all their needs, people leaving long-stay hospitals need to receive services from many different agencies, including housing and social services departments, the NHS, the local DHSS office, adult education, and voluntary and community organisations. They will need help and support in negotiating their way around the complicated variety of agencies. One way of doing this is to appoint a resource manager or coordinator for each individual.

* People leaving long-stay hospitals should also be involved in formulating their own care plans. Good individual care plans can be a useful tool for opening up opportunities for developing new skills and interests in ordinary settings. As everyone involved with the person agrees on the plan, it also helps to ensure continuity of care.

### Building individual relationships

A new approach to assessment and service planning has been pioneered in Wisconsin USA, and has been used in a few places in Britain, notably in North Manchester and in the London boroughs of Waltham Forest and Camden. Based on a book called Getting to Know You(1), it involves mental health workers in developing relationships with individual patients in long-stay hospitals so that better information exists on which to base service plans. The suggestion that staff do not know the people they care for may come as a shock. It is difficult for staff to accept that they do not know the people they spend their working lives with. However, the whole aim of 'getting to know you' is to disrupt received ideas and give staff a different perspective on what people need.

Getting to know someone is not the same as taking a case history or conducting a clinical interview. The information sought is more wide-ranging, covering all aspects of a person's life. The aim is to produce a picture of that person which reflects their individuality - their needs and wishes, intentions, hopes, interests and strengths - not just their disabilities. The quality and level of change that is described in this book can only come about if services are planned for individuals rather than for groups of people with disabilities.

Most mental health workers are regularly involved in carrying out individual assessments. But assessments are usually problem oriented; for example, 'What shall we do about Mrs Jones' loss of weight?'. A standard assessment would follow the lines of:

> Mrs Jones is losing weight because she is not eating;
>
> she is not eating because she is depressed;
>
> she is depressed because her husband has died;
>
> we must treat her depression.

This assessment is based solely on the presenting problem, that is, the depression. Mrs Jones is simply a name attached to 'the depression'. It could just as easily be Mr Brown or Miss Green. What about Mrs Jones's human needs such as:

her preferences and decisions about her life;

her need to be treated as an individual, not as a member of a group called depressed patients;

her personal ties with people, places and possessions;

her right to be able to experience new things, learn new skills and develop new aims in her life;

her need to live, work and socialise in a normal community of her choice;

her right to participate in this community as an equal member.

This list could be added to indefinitely, but it does give some idea of how service planning horizons could be expanded once a person's problem stops being the most important thing about them. Thinking about a person in terms of their disability limits the options for meeting their needs. 'Getting to know you' can make an individual 'come alive' so that new ways of meeting their individual and human needs become apparent.

During 'getting to know you', information is obtained about an individual in a number of ways. The areas which need to be covered are summarised in the following series of questions:

Who is this person?

What is their life like now?

Does the person have a family/other natural networks and what is the extent of their involvement with them?

How did this person come to be here?

What previous contact has this person had with the service system?

What happens in their life?

What do they need help with?

What will happen to this individual if nothing changes?*

The person is the most important source of information. Other information will be obtained by spending time with them, observing any programme of activities, sharing meals, joining in any leisure pursuits and generally experiencing what their life is like. A great deal can be learnt by sitting quietly in a day room for an hour, soaking up the atmosphere. The assessor will learn from the individual about important people in their life, that is staff, friends, family and other contacts. All of these will be important additional sources of information. Records and files will also provide some information, but this may not be accurate and will focus on the person's disability.

The attitudes and values staff bring to 'getting to know you' are as important as the information collected. Putting the person first can be difficult for staff who are used to making traditional assessments. For example, someone who is isolated might be assessed as needing to go to a day centre. In everyday language, we would say that this person needs a range of opportunities to meet other people and help and support in making and maintaining relationships.

Putting the individual first also means that 'getting to know you' is a technique practised <u>with</u> people not <u>on</u> them. 'Getting to know you' is sometimes used as a general information gathering exercise or even as part of a staff training programme without any intention of maintaining contact with that individual or developing services for them. Patients on long-stay wards are used to people flitting in and out of their lives. This is a devaluing experience in itself, but to establish relationships with people for reasons not directly concerned with their own benefit, to raise their expectations and then disappear, is clearly undesirable practice.

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* Adapted from unpublished work by John O'Brien

Getting to know someone in this way is obviously time-consuming. Mental health workers may think that they already get to know the people they serve when making an assessment and therefore do not need to change their working practices. They should ask themselves whether they really do achieve a description of an individual's life from that person's perspective and how well they develop a sense of the person's environment and social relationships.

How might 'getting to know you' work in practice? Two examples are outlined below:

* Two social services officers from the London borough of Camden and two hospital social workers got to know five elderly men in a long-stay psychiatric hospital. The two social services officers put the planning process into operation on the men's behalf. They arranged housing for them and over a period of 18 months created social networks to replace those they had lost. The two hospital social workers kept in touch with the men. Advocates were found for the men of roughly the same age and background with some shared experiences in their past lives. They came from the part of Camden that the men were moving to. The men rejected the first house through their advocates, saying that the street was too noisy and there was too much traffic. Another house was found for them and the men have now moved in.

* In east London, a local voluntary organisation, Waltham Forest MIND, employed a community resettlement team to spend several months on three long-stay wards in a psychiatric hospital getting to know the patients and staff. In the meantime, a range of ordinary housing was being developed for people who wanted to move to that type of accommodation. The ward staff were initially very sceptical about the ability of any of their patients to live in the community; but gradually became more positive about the project. The resettlement team were able to build relationships with the people moving out over a long period and knew them well by the time they all moved to the community. The team continued to work with the people in their new homes, building on what they had learnt in the hospital.

Used purposefully, 'getting to know you' can lead to the development of services which are needed and wanted. Working in a new way has attractions for staff; it can increase enthusiasm and commitment to the new service and build staff confidence and morale. However, before trying to implement 'getting to know you', staff need time to think through the rationale of working in this way with people living in long-stay hospitals and to examine the attitudes and beliefs that underlie their use of this method.

## Resource Management

In an institution, by definition, all an individual's needs are met under one roof. In the community, things are very different. People need services from a large and confusing array of agencies, some of which are vast bureaucracies while others are little-known or very localised community facilities. They need help with arranging housing, personal income, work or some other meaningful daytime occupation, education, leisure and health problems. People leaving long-stay hospitals will need a great deal of support in making the necessary contacts and arrangements. We envisage that a resource manager would be appointed to coordinate all these different elements and ensure that needs were being met effectively and appropriately.

### Resource managers, case managers and keyworkers

Resource management is more commonly referred to as case management. In our view, the latter name does not adequately describe the work that needs to be done. The overtones of a clinical case suggest that it is to do with treatment or therapy. It therefore follows that case management is concerned with coordinating access to conventional mental health services and facilities, rather than to a range of ordinary as well as specialist facilities.

The confusion with treatment explains why case management and the key worker concept are often thought to be the same thing. In multidisciplinary teams, one staff member may agree to take on most of the work with an individual following assessment. The team member becomes the key worker for that person. In addition to carrying out direct professional work, the key worker also involves other team members as necessary, liaises with outside agencies, reports back to the team on the case and generally has oversight of the case until discharge. The resource manager differs from the key worker in that they may not necessarily be involved in direct work with the client although there will be regular contact.

There is some disagreement over this distinction. For example, Lamb, writing from an American perspective, maintains that resource management should be a function of the primary therapist, because the person who works most closely with an individual has the best knowledge of their needs.(2) The argument against this arrangement is that the primary therapist or key worker may be more interested in direct work than in liaison with other services and may assign low priority to this task. Lamb argues that this problem could be overcome by delegating the more mundane tasks, such as accompanying someone to a housing office, to paraprofessionals; but if several people are doing the coordinating, this seems to negate many of the advantages of having a single resource manager.

It should also be recognised that coordinating resources for people with long-term psychiatric disabilities is a difficult and time-consuming task which cannot be simply tacked on to professional work as an afterthought. If this task is to be carried out by a key worker, sufficient time needs to be allocated for it in addition to their everyday work.

Although the chief function of the resource manager is coordination, most models of the process add on a number of other activities - case finding, assessment, liaison with key individuals and agencies, monitoring and advocacy. Good personal knowledge of local resources and facilities is implicit in these tasks, but is not usually specified.

### Case finding and assessment

Case finding may not necessarily be an important function of the resource manager. In a situation where a hospital is being closed and all the people who live there are being resettled into ordinary housing, the client group is clearly defined. Where the resource manager is coordinating services for people already living in the community, efforts will have to be made to identify those people most in need of services. Certain groups, such as homeless people and people from ethnic minorities, are known to be under-served; strategies will need to be thought out to reach these groups. The resource manager may have to adopt some of the techniques of community development work and enlist the help of members of these communities to identify people in need and to help them approach the service providers.

Assessment may also not fall within the remit of the resource manager. This depends very much on how assessment is interpreted. If it is seen as a screening process to determine whether an individual is suitable for inclusion in a scheme, then it could be a function of the resource manager for people living in their own homes. However, where people are being transferred from hospital to community, this type of gatekeeping should not occur. The decision to move out of hospital and live as an ordinary member of the community should be based on individual choice. Where assessment means an initial description of a person's needs, this could be undertaken by the resource manager as part of the 'getting to know you' process. Recurring assessments are part of the individual planning and review process.

### Liaison, monitoring and review

An individual care plan will form the basis on which the services a person receives can be monitored and reviewed. The resource manager may or may not be responsible for drawing up the care plan, which is described at length in the next section. However, monitoring of services presents a number of difficulties which may make the resource management function difficult to implement.

In North America, case managers tend to be drawn from the more junior members of the mental health professions. They are able to secure services from individuals and organisations over which they have no authority because they are usually in a position to buy services or apply some financial sanction. The British system of funding health and social services is currently very different from the American one. This means that the resource manager, who lacks professional or managerial authority, would need considerable powers of persuasion to obtain services from higher-ranking professionals or outside organisations.

Although consumers do not have purchasing power in British mental health services, there are some slight signs of a trend towards that sort of budgeting here. However, there are very few examples in practice and those that exist emanate from single agencies where all an individual's needs can be met within that agency or from community resources. The Kent Community Care Scheme and the Age Concern Action Research Project, based in Newham and Ipswich, are examples. Both projects aim to help older people with physical or mental health problems to remain in their own homes instead of being admitted to residential care. In both cases, decentralised budgeting is used to control the amount spent on an individual and to encourage workers to seek innovative solutions to clients' needs. Both projects have successfully recruited unqualified local people to meet basic caring needs. This was made possible through control of the budget by field-level staff.

In Exeter, a small budget was allocated to a scheme to provide home support for elderly mentally ill people. The North Derbyshire Mental Health Services Project makes small budgets available to self-help groups. The members administer the budget themselves. The availability of small, decentralised budgets to buy in whatever help is needed and to provide a richer lifestyle for people is likely to become an increasingly prominent feature of community mental health services.

## Advocacy and empowerment

Inevitably, the resource manager will identify needs which cannot be immediately met by existing services. The question then arises whether the resource manager should act as advocate on behalf of an individual and campaign for those services to be provided. In our view, people who are unable to articulate their own needs and wishes need independent advocates without vested interest in the existing service system. It is very difficult to be an effective critic of the service of which you are a part. Most jobs require that demands for new service developments go through the appropriate channels, and this means that they could be ignored. Although they cannot be an advocate, resource managers can work in a way which empowers the individual they serve. They can encourage people to state preferences and to make choices - to see themselves as citizens with the same rights and value as other citizens.

Rose and Black have outlined a model of case management which emphasises rights and entitlements. They concentrate on encouraging people to become active participants in the community rather than passive consumers of poor quality or non-existent services. One of the valuable points they make is the need for resource managers to have good knowledge of the functions and responsibilities of different service providing agencies: who has the power to make decisions; how informal systems work; and the formal complaints machinery.(3)

## **Knowing what is available**

Because the aim of the new mental health service is community participation, the resource manager will have to link people with existing community facilities and networks. This means that good knowledge of how the local community works is essential. This may involve the resource manager in making contact with key local figures, such as political, church and trade union leaders, members of community and voluntary groups, and so on. In order to participate in community life at any level people need an income. Therefore, they will need to be provided with good information on welfare benefits. Of course, one person cannot collect all the information that is needed. Data collection needs to be shared among several workers who work as a group or team.

## Individual plans

Individual care plans are a formalised way of achieving continuity of care for individuals. Although well established in North America, individual plans (IPs) are still new in this country. They have mainly been introduced here in services for people with learning disabilities. The procedures for setting up one version of an IP system have been described by Blunden.

The centre of this system is a six-monthly meeting, attended by the individual concerned, members of their family and key professionals, at which the plan is agreed. Before the first planning meeting, some initial steps have to be taken. All the key professionals involved with an individual have to agree to participate. A list of resources which will be allocated through the IP needs to be drawn up. A 'client contact' needs to be appointed for each individual; this might be the resource manager or key worker. Relevant information is collected about the individual and a strengths/needs list is drawn up. At the meeting, everyone agrees on a series of short and long-term goals which, if achieved, would help to meet an identified need. Accountability for carrying out specific tasks is clearly defined. Action and the person responsible are recorded in the plan which is written after the meeting and circulated to those who were present. People know clearly who is responsible for which tasks and can pass on information through the IP contact. At the end of six months, another meeting is held to review progress towards goals and to set fresh goals if necessary.(4)

This IP system was implemented in Wales for people with learning disabilities and has recently been evaluated. The benefits identified include better communication and information sharing as well as consumer participation in planning their own care programmes. However, progress still needs to be made in certain areas. Even though the meetings are fairly informal, individual users found it hard to contribute, which suggests the need for the development of advocacy services. Plans are not always written in practical behavioural terms and it is not always easy to assess whether goals have been achieved. The plans do not always specify goals which would facilitiate greater integration and independence. And the goals identified often relate to the needs for skills training rather than longer-term needs.(5) These conclusions suggest that even where there is a service commitment to change, it is hard to alter ingrained working practices. The attitudes and perceptions individuals and professionals have of each other are also slow to change. However, this does not mean that we should abandon our efforts. It simply means that achieving community participation for people is harder than it appears and we need to make even greater efforts.

The Welsh experience with IPs in services for people with learning disabilities can tell us something about how individual plans might be used in community mental health services. People with long-term mental health problems require opportunities for growth and self-determination whatever their level of disability. They also need maintenance and social support over a very long period, probably for the rest of their lives. There should be some way of recording short and long-term objectives and the steps needed to achieve these objectives. However, it would be quite wrong to use IPs in a way which leads to people being viewed exclusively as a series of problems to be solved by achieving certain goals.

The problem-solving approach of the IP system is used to bring about improvements in social functioning. It has some affinity with the task-centred method in social work.(6) In both, the importance of involving people in articulating problem areas and contributing to solutions is stressed. In task-centred social work, the emphasis is on small goals achieved by incremental steps. The aim of closing a case quickly is not useful in community care, but the method may help to bring about small changes in behaviour.

IPs are not produced solely for the benefit of their subjects. They are also a means of information for professionals. The growth of interest over the past few years in local mental health service case registers is evidence of the need for such information.(7) In our view, case registers can be helpful in ensuring that people with the greatest needs receive the services they are entitled to. They can also provide a check on whether services are being distributed equitably between different groups in the catchment population; for example, are people from ethnic minorities receiving a fair share of services? However, case registers have tended to be strong on diagnosis and weak on solutions to problems. This may be something to do with the purpose for which they were designed. Standardised case registers are generally used to compare data from different centres. They are more concerned with external information needs than with the internal information needs generated by a project team. In longitudinal case records, there seems little value in recording initial diagnoses. It may be more helpful to formulate individual problems in a way which suggests interventions. Clearly, teams need to give much thought to how information about individuals should be recorded. However, there does seem to be room for developing a register based on the IP model rather than on current examples of mental health services registers.

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# CHAPTER 6

## BRICKS AND MORTAR

### What Kind of Housing?

We know from research something about the kind of housing that people discharged from hospital would like to live in. In a recent study carried out in two London boroughs, a majority of those interviewed said that they wanted to live in independent, permanent accommodation.(1) Some conclusions about preferred types of housing can also be drawn from the experiences that existing types of specialist housing provide for mentally ill people. How would you feel about living in a large hostel that stood out from the surrounding neighbourhood or in a house with eight or nine other ex-patients, none of whom has anything to do during the day? No one values living in housing which is institutional in appearance or in practice.

Ordinary housing can be used to provide a small-scale network service which can provide both accommodation and support services. Within this service, there should be a variety of housing which can be adapted to meet individual needs. Most people choose to live either by themselves or with one or two other people so there should be a range of one to three-bedroomed flats and houses to choose from. One or two four-bedroomed houses could be provided but, on the the whole, we believe that a better quality of life can be achieved in smaller groups.

Apart from size, there are three other major considerations in choosing ordinary housing:

- The housing should be dispersed so that there is no risk of creating small communities of mentally ill people. Some thought should also be given to the proximity of housing or day facilities for other groups, such as people with a mental or physical handicap. Grouping such people together, because they are so devalued by society, will draw attention to them and hinder their integration into the local community. To prevent several sites being developed in the same neighbourhood, there needs to be good cooperation and communication betweeen the various agencies involved. A local authority planning or housing department could possibly play a coordinating role in gathering information about housing developments for devalued people in order to prevent grouping them together.

Ideally, there should not be more than one house in each street, although this would depend on other factors such as the length of the street, availability of housing, and so on. The properties should be spread out over a small locality, perhaps two miles in radius, and be within walking distance of each other. This would allow staff to work easily; it cannot be assumed they have a car. Each house or flat should have on-street parking close by to allow ease of access.

- The properties should be close to shops and all the other ordinary community facilities. They should be within easy reach of an individual's workplace or the community/day centre that they might use during the the day. Proximity to public transport routes is also an important consideration as it is easy for mentally ill people to become isolated on large estates.

  In rural areas it may not be possible to locate housing within a small neighbourhood where all an individual's needs can be met. The housing network may be more widely flung and development workers may therefore have to think of imaginative ways of meeting day care needs on an outreach basis. The North Derbyshire Mental Health Services Project, based in Chesterfield, has overcome some of the problems of covering a large rural area by developing self-help support groups in the outlying market towns of the Peak District. A project worker provides back-up to each group but they are essentially self-governing.

- As noise is a well-known cause of housing stress, properties should be in quiet streets where there is no continuous or intermittent noise from road or rail traffic, factories, and schools. As it is not always possible to meet this requirement in cities, various kinds of sound insulation, such as double glazing, should be considered.

> As well as reducing noise from outside, some attention should also be paid to creating a quiet environment within the house. Insulation between floors is essential to cut down noise from upstairs flats.

Ordinary housing can be converted by careful design to provide a variety of accommodation to suit individual needs. Normally tenants should have their own room and there should be a shared sittingroom. A spare room for overnight visitors would be useful. Some tenants may have exclusive use of facilities such as kitchens and bathrooms. Sharing intensively-used facilities is a potential source of conflict, but careful design can overcome some of these problems. For example, a three-bedroomed house could be converted to provide two semi self-contained units for one and two people respectively, with a shared sittingroom. In another three-bedroomed house, the residents might share all the facilities. Decisions about design have to be taken in the light of adequate knowledge of an individual's wishes, needs and abilities.

**Move-on accommodation**

Ordinary housing can be used to provide permanent homes for people discharged from long-stay hospitals. However, most people move house from time to time and people with a mental illness are no exception. They may wish to change flatmates or, with increasing age, may wish to move to a ground-floor flat closer to the shops. The housing network therefore has to budget for a few voids at any one time so that some movement between properties can take place.

It is important to distinguish between a freely-taken decision to move and the 'ladder' model of rehabilitation where people are always on the move - from stepping-stones villa to half-way house to rehabilitation hostel to independent housing. People should not move solely because their needs for staff support have increased; services should always be brought to the person where possible. People should only have to move out of their own home if the service they need cannot be provided there. They should stay away for as short a time as possible and return home afterwards.

## What Housing is Available?

Ordinary housing can be found but, again, it is not possible to prescribe exactly what sort of housing should be used. In practice, people on low incomes or benefits have a restricted choice of housing. Currently, people leaving hospital can:

a return to their own or their family's home;

b move into local authority or housing association ordinary rented accommodation;

c stay in specialist accommodation - for example, hostels or group homes, perhaps for a limited period.

d use emergency accommodation.

Most ordinary housing schemes have made use of local authority rented accommodation or have developed special projects in conjunction with housing associations. The type of housing used and the way it is financed depends very much on local factors, such as relationships between the statutory bodies and with voluntary organisations.

### Local authority housing

Some housing schemes have been successful in making extensive use of public sector housing. Under the Housing (Homeless Persons) Act 1977, local authorities have a duty to rehouse people deemed 'vulnerable', which includes mentally ill people. However, not all local authorities will accept people as homeless while they are still in hospital. Some housing departments operate a quota system so that priority can be given to mentally ill people. Where local authority housing is used, it is important to involve housing department staff at an early stage so that they are aware of the needs of the people they are being asked to rehouse. Although local authorities are likely to become an increasingly important source of housing for mentally ill people, it is still unusual for housing departments to be represented on joint planning teams (JPTs). It is especially important to involve them in housing sub-groups of JPTs or in community-based resettlement planning groups.

In addition to general information about the needs of mentally ill people, housing department staff also need adequate information about individuals so that they can allocate suitable housing. One of the best ways for housing staff to find out what people need is to get to know them before making an allocation. Housing staff should also be aware of the process of social devaluation and the need to counteract this by choosing the most socially-valued housing option. It may be tempting for housing departments to allocate 'hard-to-let' accommodation, but they should be aware that people leaving psychiatric hospital have perhaps greater need of high-quality accommodation than other people. Mentally ill people should not be allocated housing which will lead to a vicious circle of stress, breakdown and readmission to hospital. Some housing departments now refer to hard-to-let tower blocks as 'vertical sheltered accommodation'; it is up to care providers to ensure that housing authorities have adequate information about the needs of people with severe disabilities, so that this type of housing is not allocated.

Similarly, mentally ill people may need greater protection from crime than other people. People with disabilities, whether psychological or physical, are particularly vulnerable to becoming victims, so housing on estates with high rates of vandalism and crime should never be allocated to them.

## Housing associations

Many housing associations are now interested in developing special projects for people leaving psychiatric care. Joint finance and, more recently, housing association grants have made it possible for health authorities to supply part or all the funds for a housing association to purchase a house. Health authorities can also provide topping-up revenue contributions. The arrangements for financing special housing are complex and are covered in greater depth elsewhere.(2) As housing associations have expertise in the acquisition and management of property, but lack knowledge of mental health services, they are keen to work with statutory or voluntary agencies who know more about the needs of mentally ill people. The usual arrangement is that housing associations provide the buildings in partnership with a statutory or voluntary agency which then acts as the managing agent of the property and provides care and support to the tenants.

In order to overcome some of the problems of shared responsibilities, some London housing associations have initiated the notion of the consortium, as discussed above. Technically, consortia could also employ and manage community care staff, but this function is not well-developed as yet.

Whether a consortium is set up or not, effective liaison is essential for the successful development of a housing project. The siting of a house should be planned jointly by health and social services, the housing authority and housing association working in that area. The planning of each house should be carried out jointly by the caring agency, the housing agency and the people who will live there.

## Family sponsorship and lodgings

For some people, a family sponsorship arrangement may provide the most suitable form of accommodation. Some local authorities operate adult care schemes which enable them to match individuals with suitable carers. Even very severely disabled people can be resettled in this way.

Lodgings for mentally ill people have acquired a bad name. They have become associated with seaside boarding houses and profiteering landlords. Little or no care is provided and individuals are quietly forgotten. However, for some groups of people, such as single, possibly older men, taking lodgings in someone else's home is a normal and socially accepted type of accommodation. There is no reason why the staff in a housing network should not support one or two people in lodgings if this was thought to be the most appropriate type of accommodation for them. The London Borough of Camden, as part of its adult care scheme, has recruited landladies who are prepared to offer accommodation to people with mental health problems. Although the borough has pioneered this type of adult care scheme, the disadvantage is that mentally ill people are placed outside the borough and consequently lose touch with their normal social networks. Landladies need to be given training in providing care to people who are very institutionalised and need to know that professional support can be summoned whenever they need it.

Family sponsorship and lodgings seem to work best in rural areas, perhaps because there is a higher degree of community integration. In some places landladies are able to join a support group so that they can meet to exchange information and discuss any problems.

## Ordinary Housing in Practice

Although it is possible to describe the kind of housing that is wanted, the road to establishing people in ordinary housing is paved with rules and regulations, which may be in conflict with the principles outlined earlier.

REGISTRATION Small-scale housing, provided by a voluntary agency, may have to be registered with the local authority to comply with the Registered Homes Act 1984, although this legislation is under review and houses for up to six people may be exempted in future. Apart from the costs of registration, the Act stipulates certain requirements which are institutionalising in effect, for example, registered homes have to display a certificate of registration. The owner of a residential home would also have to liaise with the local fire and environmental health officers, which would introduce another set of potentially institutionalising regulations. Guidance on standards is contained in Home life: a code of practice for residential care.(3) In a values-based service the aim would be to provide housing which did not stand out from neighbouring houses and which, to all intents and purposes, looked like an ordinary home. The standards imposed by the Act would appear to run counter to this aim.

However, the principle of setting external standards for the voluntary and private sectors is a good one in that it should lead to a universally higher quality of care. People leaving long-stay psychiatric hospitals have a right to good accommodation and care and need to be protected both from unscrupulous landlords and incompetent management. The important point is that appropriate standards are needed which provide protection and enhance quality of life but do not inhibit ordinary living.

PLANNING REGULATIONS Some constraints are also imposed by the planning regulations. Planning permission should not normally be required for ordinary housing as some essential living areas will usually be shared. It can therefore be argued that there is no change of use and that the property should be classed as a single dwelling. However, if houses are divided up into entirely self-contained units, planning permission must be sought.

In practice, most housing associations will wish to approach the local planning committee and inform them of their intentions. It is difficult to provide authoritative guidance on planning applications, as planning committees have powers of discretion. There is no standard approach which can be recommended.

Although it should be possible to have an ordinary house for two or three people classed as a single dwelling, housing providers should still consider whether to adopt the fire and environmental health standards which would be imposed on a house in multiple occupation. It can be argued that these are institutionalising and will make the house different from other houses in the street. It can also be argued that much British housing is old, of poor quality and does not meet modern building standards. As the aim of a residential service is to provide high-quality housing, it is better to negotiate with local officers a set of appropriate standards which are not incompatible with ordinary living.

TENANTS AND LICENSEES Another dilemma is the question of whether the residents should be tenants or licensees. Tenants and licensees have differing rights and status but, in general terms, tenants have greater rights. Tenancy confers security of tenure as well as certain obligations and responsibilities. It would therefore seem preferable for people living in ordinary housing to become tenants. However, some housing schemes have opted for a system of licences because this entitles residents to claim the higher rate of DHSS board and lodgings allowance and thus slightly increase their disposable personal income. It is debatable whether it is more socially valued to be a tenant or to have more money to spend, and in fact some tenants are eligible for board and lodging levels of payment.

The residents should be fully involved, as a matter of good housing management, in decisions about whether to opt for a system of licences or tenancy agreements. Some provision needs to be made to charge employed people lower rents as their net income may be less than that of people in receipt of benefit.

## Home at Last!

It can be seen that the principle of normalisation does not provide easy answers to developing housing for people with long-term mental illness. Our intention has been to pose some of the questions raised by deinstitutionalisation. With goodwill, hard work and imagination, it may be possible to find some of the answers.

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# CHAPTER 7

## PROVIDING SUPPORT SERVICES

Good, permanent accommodation is the cornerstone of community care, but it is only the beginning. As well as housing, people leaving long-stay psychiatric hospitals will need help with structuring their day. They will also need support in using ordinary community facilities, such as shops, cafes, education, sport and leisure facilities, which offer opportunities to mix with ordinary, valued citizens. In order to achieve this level of integration, people moving back to the community will need to have a system of personal support set up for them, probably for the rest of their lives.

Although community care has been talked about for the last 30 years, very little is known about the type of flexible, responsive support services that are needed to maintain people with long-term mental illness in the community. There has been greater momentum behind the development of community mental health teams and centres where the emphasis is on acute care, rather than on people with long-term problems. Although there are now several supported housing schemes in the UK they are still unusual. Community care is developing in a way in which it is all too easy for the needs and interests of those with the most severe disabilities to be overlooked. This chapter, therefore, is about the tasks that will need to be carried out in a supported housing service; later we consider how these tasks will be organised and the implications for professional work.

### What is a Support Service?

Independent living is the social norm for most adult households. However, individuals who may have spent many years in institutions where decisions were routinely taken for them are unlikely to have the experience to cope with many aspects of everyday life. In addition, the skills required to cope with life in a hospital, hostel or day service are very different from those required to live an ordinary life in the community. The aim of the new service is to help people to live as independently as possible in the least restrictive environment. Where this is not possible, support staff will need to intervene to find ways of meeting an individual's perceived needs.

Adequate information about individual requirements should be found in the individual plan, which will have been started before discharge from hospital and updated and expanded at regular intervals subsequently.

In any support system, there is an inherent danger that the level of support will smother initiative and prevent people from taking control over their lives. Support staff are therefore in the challenging position of having to meet genuine needs but, at the same time, encourage initiative and positive risk taking. Institutionalised services encouraged dependence; in order to avoid recreating the same problems in a new service, support should be provided flexibly, taking account of individual progress. Staff should match their response to individual needs, withdrawing as people learn to do more things for themselves. Decisions about providing support in this flexible way need to be thought out at management level. However, staff need to use their own judgment about when to intervene and take over a task for the person they are supporting.

People should not be prevented from attempting new tasks or having new experiences because of predetermined assumptions about their capacity for change and growth. Valuing someone means that personal growth is always possible, whatever an individual's level of disability.

### Expanding social networks

People with severe psychological disabilities are no different from the rest of us in their need for a social network to support them in a neighbourhood or community. Unfortunately, their disabilities are often expressed in such a way that they have difficulty maintaining such networks. Service providers do not always recognise the tenuous and sometimes invisible networks people rely on to sustain them in the community. Even a few weeks in hospital is long enough for some people to lose their homes, forcing them to find somewhere else to live and develop new acquaintances.

A major service aim will therefore be to maintain or extend social networks. Social networks are the people we know or recognise as friends, family, casual relationships and familiar faces that make up our social world. Some elements of social networks are stable, but there is also a tendency towards change as relationships change in quality or we make or lose contact with people.

Social networks should be recognised and allowed to develop. People with few friends and new surroundings will need help in developing these networks. Care staff will need to think of appropriate, non-intrusive and valued ways of building networks. It is generally thought that those who have severe mental health problems are loners who prefer not to have contact with other people. In fact, their lives are often devoid of the shared experiences which make social contact possible and natural for most people. They have often lost touch with their past, but trips to see family and old friends can help to restore a sense of continuity in time and place. Visits to cafes, pubs, social clubs, drop-in centres, recreational facilities and adult education courses provide new experiences and a chance to mix with new people. However, people should not have their whole lives arranged for them; there should also be some scope for spontaneity.

Visits and trips should normally take place in small groups of twos and threes. The special minibus for a large group outing is unnecessary. A trip with one or two friends on public transport offers greater potential for social integration. Occasional large group gatherings may be a good idea - to celebrate a special occasion such as Christmas or a birthday or if someone's leaving. It is important that networks are built in ordinary, typical settings that might be used by any member of the community. People who are negatively valued by society gain in status through contact with more valued people in ordinary settings.

**Skills for living**

More often than not, residential and hospital services are ineffective in teaching people the skills that will allow them to function in the community as competently as they are able. The more time people spend away from their social networks, the more likely they are to lose them and the skills required to make and sustain friendships.

People with severe mental health problems are not a homogeneous group. Although the impact of the disability may affect their social functioning in similar ways, each person still retains a unique individual pattern of concern, motivation and tension. They experience significant difficulties in coping with ordinary daily activities, because of the impact of their disability and the response of society to their experiences. It is often the impact of the disability on the person's social functioning which brings them into contact with formal mental health services, not their level of pathology. To get away from the services the person usually has to show that their symptoms have decreased, not that they are better able to cope and function socially. People who function well socially have a better social image and a correspondingly greater chance of being accepted as a full member of the community.

Most of the skills that people need to acquire, apart from basic safety skills, are best learnt in the environment in which they will be used rather than in hospital prior to discharge. This is different from the 'ladder' model of rehabilitation, which is concerned with preparing people for increasingly independent stages of living to which they must graduate. The staff will need to provide support in daily living skills, such as self-care, housework, shopping and budgeting. For some people with a background of institutionalisation, it will be a question of relearning old skills; for others, it will mean learning skills that they never possessed. Apart from tasks centred around running a home, the person may also need help to interact with valued members of the community - at work or other day time activities - using public transport, visiting shops, cafes, the pub and other ordinary community facilities. A great deal of help may be needed at first, but the level of support can be gradually reduced as people become more skilled.

The need to teach skills in real environments demands a certain flexibility of the staff. They need to be prepared to work in different settings, in a person's home or elsewhere in the community, and to withdraw or increase support as needed. They also need skills in negotiation in order to be able to meet an individual's needs and wishes in ordinary community settings.

How can such flexible support be provided? As an example, we shall look at the work of the Peter Bedford Trust, a voluntary organisation which provides housing and employment for over 100 people with institutional backgrounds. The Trust employs a team of 3 full-time support workers who combine traditional housing management functions with support work. They assist with everyday tasks and also encourage the tenants to carry these out for themselves. Help is provided with household cleaning, personal hygiene, financial advice, education and liaison with mental health services. Most of the tenants take part in the Trust work schemes during the day. The level of support varies according to individual needs and ranges from weekly contact to collect the rent, to regular visiting or even staying over the weekend with someone who is unwell. A small number of tenants who lack basic living skills do not go out to work and three additional part-time workers provide intensive training for these people in their own homes. An education and training officer has been appointed to develop leisure and educational opportunities for the tenants in non-segregated community settings. His work also includes the design of training programmes for the part-time support workers. In addition, he provides education for trainers in institutions on the type of skills that people discharged from long-stay hospitals need in the community.

## Crisis care

Despite the existence of a long-term support system, service users may require intensive support during crises and may even need to move out of their home for a while. The way in which such help is to be provided needs to be considered at the development stage of any project. Where there are no resident staff, an emergency service needs to be designed which can be quickly activated if, for example, a tenant becomes acutely distressed. The Forest Community Project, run by Waltham Forest MIND has installed an expensive, but effective, mobile telephone system so that the duty worker can always be contacted should the need arise. Good links should also be developed with the community mental health team or other mental health services so that they can be called in should the need arise.

In general, the 'least moves' principle also applies to acute care. Intensive care and support should be provided in a person's own home, or at least in their own locality. People should not have to travel far to find the crisis support services they need.

Some local mental health services have found ways of providing intensive support over a short period. For example, the North Derbyshire Mental Health Services Project has a peripatetic rehabilitation team who are able to provide 24-hour care in a tenant's home if necessary. The project has also allocated a small budget to its network of self-help support groups so that if one member is acutely distressed, practical help as well as support can be quickly provided.

It is perhaps the issue of asylum which requires the greatest effort of imagination from staff moving to the new service. Asylum can be provided in the community, not just in large distant hospitals. Removal to a more restrictive environment should only be considered when people are a danger to themselves or to others, or when the home situation becomes intolerable. There may be benefits in organising a safe place in the community where people can stay for 24 or 48 hours and then return to their own home. It is possible, with imagination, to organise this type of facility on a community basis. Some projects, such as the Wainwright Crescent Support Unit in Sheffield, have developed a network of housing from an existing hostel base; some of the hostel beds are used as a refuge when people cannot be looked after at home. The Coventry Crisis Intervention Team provides a community-based residential and day care facility, which could potentially be used by people living in ordinary housing.

## Personal income

People on long-term benefit are poor and this severely restricts the number of opportunities they have to join in ordinary social activities. Staff need to be aware of the need to increase income. Support workers cannot be expected to become experts on the social security system but they need to have some knowledge of welfare benefits and to know where to turn for expert advice.

The financial arrangements surrounding the transfer from hospital to community and for handling a tenant's income afterwards can be particularly devaluing. Furnishing a home to a high standard and buying new clothes are important to enhancing self image, yet problems in getting the money for such essential items often causes the person to feel even more devalued.

Control over personal finances is an important step towards citizenship and tenants should not be deprived of this responsibility. They should normally be responsible for paying their own rent, the only sanction they have over their landlord.

## Housing management

This is a basic task in a residential service and will usually consist of arranging lettings, collecting the rent and advising the resident on repairs and maintenance. Where local authority housing is used, these tasks will normally be carried out by a housing worker, and direct care and support will be provided by social services. A small voluntary organisation supporting three or four people in a housing association property may employ one worker to carry out both management and support tasks.

There is a potential conflict of interest between representing the landlord and providing care and support to the tenant. There is much disagreement among service providers about whether one task interferes with the other. Housing management and, for example, counselling, appear to be quite separate functions. However, those who favour the one-worker arrangement argue that housing staff are regularly drawn into tenants' personal problems and that their friendly advice may be more helpful than counselling from an 'official' source.

Whatever decisions are taken about housing management, it is important to recognise that there is potential for conflict. Projects intending to combine both functions should consider at the outset how rent arrears or failure to look after the accommodation will be dealt with and how this will affect the caring relationship.

## Developing work opportunities and leisure

It is beyond the scope of this book to look in detail at work and daytime activities. However, people resettled in the community will need some meaningful way of occupying their time. Although work is the most valued form of occupation, high unemployment rates make it likely that some other form of occupation will have to be organised. In addition, most ordinary housing schemes are financed in such a way that people in employment could not afford to pay the charges. Differential charges can be made for people in work, but there is no incentive for agencies to find work for their tenants.

Some of the aspects of employment that people value are payment, status, a structure to the day, social contact and a chance to get out of the house. Given the difficulties in finding work for people with long-term mental health problems, some way of using time purposefully will have to be organised, incorporating some of the beneficial aspects of work. Opportunities to build on an individual's existing skills and interests should be sought through ordinary community facilities such as adult education and leisure facilities.

## Organising the work

How can the kind of support described above be provided? Community mental health teams are being developed, which could do some of the work. On the whole, however, they are showing a greater interest in acute care than in working with people with long-term problems. Existing primary care services also have a role - general practitioners, community psychiatric nurses and social services. GPs tend not to have the training or supervision to work with people with long-term needs, although this may change as more GPs receive this sort of training. The quality of life envisaged in this book could not be achieved through just occasional visits from a nurse or social worker. A specialist support service has to be developed which can respond flexibly and quickly to individual needs. Two basic approaches are evolving to meet this need and are briefly summarised below.

1 An independent worker or team of workers provides care and support to tenants in one or more houses dispersed over a small locality. There are links with health and social services staff who may be called in to provide emergency care if needed. This model is usually chosen by voluntary organisations who develop housing projects in conjunction with housing associations. If a voluntary agency has a single house supported by one worker there may be problems in providing cover for holidays or sick leave. The advantage of a team is that the workers can get to know all the tenants so that individuals do not experience a loss of continuity of care if their regular worker is absent. Training and supervision is also easier to arrange for a team than for individuals. Because of the lack of training opportunities elsewhere, the team would be likely to arrange its own training programme. An individual worker would not have the resources to do this. The variety of skills within a generic team could also potentially provide richer experiences for tenants, although the importance of interpersonal skills should not be overlooked.

This approach is being developed by Waltham Forest MIND. Set up to develop a pilot supported housing service, the Forest Community Project is using a team of generic workers to provide care and support to people with a long history of psychiatric disabilities who now live in a small number of houses scattered over one neighbourhood. Most members of the team are mental health professionals. Outside professional services are drawn on as necessary. The team is also developing a community centre which will provide an office base for the staff and a social facility, including a snack bar, for the tenants and local community.

2 A team of care workers, attached to a community mental health team (CMHT), provides long term support to tenants in a dispersed network of houses. Members of the CMHT also carry out regular work with the tenants and provide emergency care. There are a number of variations of this model. Some health authorities have set up CMHTs specifically to provide primary and acute care, rather than support or rehabilitation. In these cases, there may be plans to develop separate support teams at a later stage. There are advantages and disadvantages in linking the community mental health and community support teams. The support staff may be tempted into working with

people who are more immediately rewarding rather than concentrating their efforts on people with long-term needs. However, people with more minor problems can benefit from contact with people with long-term needs; both groups have something to offer each other. Access to a primary care team also means that people with long-term needs are given the same opportunities for change and growth as other people.

In the London borough of Camden, a team of domiciliary care workers is being established for a small group of tenants who have recently been discharged from a long-stay psychiatric hospital. The care workers will not necessarily be qualified in mental health work, but will receive appropriate training. This team is attached to a multidisciplinary community mental health team which will provide services to all mental health facilities within a given geographical area. Both care workers and professionals will be involved in direct work with tenants.

As well as providing support to people who have left hospital, the support staff could also provide a service to people living in their own homes. Where people are being cared for by relatives, they will also need support and counselling.

Whatever organisational structure is finally set up, some way needs to be found of coordinating the work of different agencies and individual professionals. A great deal of development work will have to go into building teams in which staff from different disciplines and backgrounds can work well together. Particular attention needs to be paid to information systems, so that the individual service user does not get lost in the complex service system. Better coordination and information sharing, which has already been discussed, is one way of overcoming this problem. In the next section, we look at how the work will be shared.

## Specialist Versus Generic Work (or who does what to whom?)

So far we have purposely focused on the work that needs to be done rather than on the specialist skills of professionals. It can be seen that much of the work involves training people in quite basic, everyday skills which most of us possess as a matter of course. This work could potentially be undertaken by unqualified staff although they will need training to recognise that they do not have innate skills. Does this mean that professional skills will become redundant in the new, community services?

## Skill-sharing and professional boundaries

The answer, of course, is that people will continue to need both specialist and generic services. However, we envisage that specialist work will not become compartmentalised as in the old hospital system; each worker will work with individual users and other colleagues so as to share and 'demystify' their professional skills. We would hope to see a genuine sharing of skills and expertise, with staff supporting and encouraging other workers to develop their knowledge in different ways. For example, a social worker would share with a nurse how to make application for home help support; a psychologist would undertake tranquiliser withdrawal with the help of an occupational therapist.

This approach entails respect for specialist training and knowledge, but also acknowledges that some skills can be shared with staff from other disciplines provided they are given time and support to learn. Users of the service will obviously benefit if individual workers expand their skills and also involve other disciplines appropriately when necessary. A number of professionals, particularly psychiatrists and nurses, should be considering whether their training, service delivery systems and management structures are appropriate to this type of work. Finally, it should not be forgotten that the personal qualities and interpersonal skills that individual workers possess are as important as professional skills.

For people working in established, interdisciplinary mental health teams, the issue of skills-sharing is more urgent. Some teams hold a weekly meeting devoted to discussing team issues; these meetings could be and often are used to explore new ways of working. Workers who have more informal contact with professionals from other disciplines (for example, a social worker in an area team), may find it more difficult to decide on an appropriate role for themselves in a new service. As in the current system, professional interest may lead to a jealous guarding of particular areas of work and a mistrust of staff who appear to be 'doing my job'. Some of these attitudes have become established over the years because of rigid inter-professional, as well as inter-agency, boundaries. In the initial stages, many teams put much effort into developing a common working philosophy and set of aims because they see the coexistence of conflicting models of mental health care as major obstacles to good interdisciplinary working relationships.

## Differing perceptions of the problem (and the solution)

The fact that different disciplines traditionally have different perspectives and approaches to mental health has reinforced the idea that cooperation is difficult or impossible. In the past, mental health services have been dominated by the medical model; there has been much debate about whether community care can instead be informed by a social model. We do not wish here to pursue the debate about the correctness of different perspectives. In practice both models will continue to coexist as at present. The new services will require facilities for the relief of acute distress, an important component of which will be medical care and treatment. However, working closely with the community will inevitably alert professional staff to the multiple causes of major, psychiatric disabilities and to the need of people with such disabilities for continuing care and support. Ideally, there should be a common professional approach to mental health care but, in reality, workers may have to liaise with members of other disciplines whose views they disagree with.

Although the debate over different models is important to professionals, it is, in our view, a diversion from the real task of providing high quality services. Whatever view is taken about the nature and course of psychiatric disabilities the principle of normalisation could still apply to the services developed. Rather than pursuing what is probably a fruitless debate about social and medical models, it may be more sensible to develop a philosophy of care on which all workers can agree. A single worker trying to develop valued lifestyles for tenants cannot make much progress on their own. There are greater opportunities to bring about change if alliances are built - between workers in the same agency or in other agencies. Staff at all levels can contribute to the process of change by seeking opportunities to build such alliances.

## Using professional skills appropriately

Workers have to carefully consider how and why they use professional skills. There is an inherent danger that they will assess needs in terms of what they can offer as professionals and the technologies that are available and fashionable. How much do people need our skills and how much do we need to practise them? A professional training can blind workers to the real needs of the people with whom they work. Research has shown that people using a day hospital did so because it was somewhere to go and meet friends, a free lunch, use of a payphone, and so on. The users expected to pay for these facilities by accepting the therapy offered by staff.(1) On the other hand, people who have been long-term recipients of psychiatric services often have basic needs unmet and ignored.

In conclusion, we envisage that the barriers that currently may exist between disciplines will be broken down. The rich variety of professional and personal skills, used in an appropriate and relevant manner, should produce a responsive and creative team of workers who can provide the optimum care for each individual.

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## References

1 Kay A and Legg C. Discharged to the community: a review of housing and support for people leaving psychiatric care. London, Good Practices in Mental Health, 1986.

# CHAPTER 8

## WORKING WITH STAFF THROUGH CHANGE

It is never easy to effect change. People who attempt to introduce new ideas are often bewildered and angry when staff resist any change in a seemingly intransigent and illogical manner. Equally staff can feel that new ideas are foisted on them in an unthinking and arrogant fashion, with little understanding of what their daily routine really entails. Both sides can quickly become entrenched and the distance between them become a battleground; the major casualties, of course, are the users themselves.

The management of change, then, requires an understanding of how people are affected by change, and a consideration of the anxieties naturally evoked during this process.

There are a number of personnel factors to be considered when contemplating the change from a hospital-based service to a community-based service. These factors should be considered by all staff. Managers especially should consider carefully and thoroughly the effects of such a change on their workforce, and should seek to work with negative feelings that may hinder the process.

### Feeling Devalued

Management must be very aware of how any message of change is delivered. Staff may interpret this message as being told that their current way of working has not only been wrong, but may even have harmed people; no individual should be expected to receive such a message about their work. We are concerned that criticisms of working practices deal with a system of care and not with what individual workers do. Management must also be seen to take full responsibility for previous working practices. Newcomers must not be critical of current practices, but realise that all systems of care are the product of a wider society. This is not to imply, however, that a critique of the current service should not be implemented, but this must be constructive planning for the future not destructive criticism of the past.

The management of change has already been discussed with regard to planning and development and the resettlement of people using the service. The need for comprehensive information sharing and flexibility has been stressed, and the same principles should apply to staff management.

## Involving Staff in Planning

Change is most effective when people have the opportunity to influence the direction of change which affects them. This means creating opportunities for people, such as the forum discussed in chapter 3 which involves service users and direct care staff in the planning, implementing and management of the new service.

Direct care staff will play the greatest role in implementing the new philosophy and thus confront the greatest difficulties. They must feel their opinions have been valued, and that their responsibility in planning for the service is reflected at all levels. There should also be clear and effective channels of communication that are continuously feeding back new thoughts and developments both up and down the structure.

Davis and Towell(1) looked at the effects of relocation in the community on both staff and users. They argue that planning for the transition should be based on six principles:

1 People should be fully informed of all proposals.

2 Individuals should be consulted about changes which may affect them.

3 Individuals should be offered skilled support in making decisions about their own future job or residence.

4 Individuals should have access to independent representation in relation to decisions about relocation.

5 Individuals should be encouraged to participate whenever possible in shaping the services in which they may be workers or users.

6 A high quality programme of development opportunities should be provided to assist people in preparing for change and equip individuals for the practice of new roles and skills.

In implementing these principles the implications for staff are an emphasis on training, redeployment and representation; for service users the emphasis will be on rehabilitation, resettlement and advocacy.

## Worries About Jobs and Accommodation

Clearly a major anxiety in any structural reorganisation is uncertainty about retaining jobs; this is not unrealistic given the present economic climate. One of the first decisions to be made by senior management has to be whether there will be job losses or not. If not then this decision should be clearly communicated to all staff at the beginning of the planning process (some authorities have done this - Exeter, for example). The redeployment plans should also be worked out and communicated to staff at an early stage.

If redundancies are necessary then management must not evade confronting this issue, as delay in doing so will fuel anxieties and resentment.

Some staff have their accommodation provided by their employer. The position with regard to staff housing must also be made clear well in advance of possible changes.

## Leaving Positively

It may be that some members of staff feel unable and/or unwilling to work in a new service. It is essential that they can make this decision in a supportive and uncritical atmosphere. It is a positive decision for a person to assess their abilities realistically and to realise that a new post is not the most suitable expression of their individual skills and resources. In no way should the person be made to feel they have 'failed' or they are not 'good enough'. Clearly, from the service viewpoint, it is better to have staff feeling they can leave and allow more appropriate people to fill the posts.

## Designing Jobs in the Community

When determining new roles for staff in a community service, managers also need to take account of more general factors associated with motivation and job satisfaction. Rees(2) cites the general reasons for working as:

a chance to use initiative at work;
good working conditions;
good working companions;
good boss;
steady, safe employment;
money;
good hours;
interest in the work itself;
opportunity for advancement;
getting credit and recognition.

These reasons might seem rather obvious once written down, but may remain unconsidered if not actually stated. It must also be recognised, of course, that people are motivated by different things; managers must take these individual differences into account when considering changing roles for staff. Rees also discusses the 'Procrustean approach' to job design, a concept relevant in many ways when developing a community service. Procrustes was a legendary figure in Greek mythology who had a special bed. His guests had to fit the bed exactly; if they were too small then he stretched them on a rack until they fitted; too long and he chopped off their feet. In a new service jobs should be allocated by:

determining what functions are necessary to fulfil people's needs; and

allocating functions to an individual worker on the basis of personal ability, rather than assigned discipline, although of course, the two may coincide.

Contrast this with the 'Procrustean approach' whereby people's needs are the luckless guests on an unchanging bed of professional skills.

## Accountability and Responsibility

### Staff concerns about responsibility

Working in an institution is a safe environment; in contrast, working in the community can seem unstructured and frightening. There are no timetables to adhere to, and staff may have very real worries about the extent to which they will have to control their work. The disappearance of the institutional hierarchy can blur the lines of responsibility and may leave staff feeling that 'anything could happen'. They may be unwilling to increase their clinical responsibility for individual users, feeling unsupported, vulnerable and on their own.

Lines of accountability and responsibility must, then, be made clear. Staff support, either in the form of individual supervision, peer supervision or staff groups, must be an integral part of a new service. Staff may feel isolated when working in the community and it is essential that measures are built in to prevent this from happening.

Staff need to discuss and explore the issue of risk with regard to the services they offer people. A hospital is a low-risk environment for both users and staff. Staff will often object to care in the community on the grounds that there is an unacceptable degree of risk - but for whom, staff or user? A major component of human dignity, regardless of disability, is the element of choice and therefore risk. Removing risk from a person's life means removing choice. This diminution of human dignity should become unacceptable in a new service.

However, increasing risk means increasing anxiety, and both staff and users need to be supported through the initial phase of readjustment. This is not, of course, an exhortation to staff to 'abandon' people to unmonitored risk in the community. Each individual should be exposed to 'reasonable risk' and this will be a decision reached by the person themselves, and staff with whom they have contact.

## Redefining work achievement

Worries about accountability and responsibility also include worries and difficulties with self-discipline. Management often cites this as a reason for not putting staff in the community - they fear staff will go off shopping and not attend to their work. This is, of course, nonsense. Staff themselves, though, may feel concerned about monitoring the content and quality of their work when suddenly all the parameters have changed. A nurse who has made 20 beds and bathed six people has a concrete measure of his or her work. How, though, does he or she evaluate a morning spent with a family in crisis, or three home visits, all of which were non-starters because the people were not at home?

Staff must be helped to evaluate their work in a different way, and use different measures of success. Attending to the physical care of 30 people in a ward for one day is an achievement, but equally, so is spending a day with just one person and thus preventing a readmission to hospital. The definition, then, of what constitutes an achievement will change in a community-based service. Managers must be alert to staff who, not making this change, come to feel demoralised and lacking in competence.

## Accountability

Medical accountability was established by Hippocrates over 2,500 years ago in his famous oath '... above all not knowingly to do harm'. Accountability is a word often used yet little understood by health workers and even less so when used in conjunction with community mental health services.

Accountability in practice means being responsible for people, things and actions, and being held responsible by another person. Accountability, then, demands an explanation and rationale for what individual staff actually do. This rationale should be based on knowledge and training, although in reality it often slips into tradition and habit. However, in a community service the familiar routine will not be there and staff may find the issue of accountability looming large in a strange and uncertain environment.

A review of the literature reveals many interpretations of professional accountability. These different aspects are summarised by Law(3) who takes accountability to be:

1 To the user, to deliver a high standard which is effective, safe and ethically good.

2 To a professional body, which controls training, maintains a register of practitioners and sets standards.

3 To colleagues; staff who delegate tasks to others, possibly less experienced, retain ultimate legal accountability, although the delegated member has responsibility for the work.

4 To a team; this is reciprocal accountability, staff members help each other to carry out coordinated care plans for users.

5 To the employing authority; staff are accountable to their employer to maintain standards, sometimes assisting in training, and conforming to locally devised policy.

**What legally constitutes negligence?**

Staff may like to remember that there is no legal duty to effect a cure.

Factors that can be construed as negligence include:

1 Failure of communication. There is a duty on the part of each staff member to ensure that the referring doctor has the necessary information about the person.

2 Keeping up to date. A duty of care owed to each user requires that staff keep reasonably conversant with professional knowledge and techniques.

3 Differing schools of thought. Where there are differing schools of thought about a treatment or approach, staff are not negligent if acting within accepted practice as defined by a responsible body skilled in that particular area. However,

staff cannot continue delivering the same treatment if a substantial body of professionals have a different opinion.

4 Deviation from normal treatment. If a client is injured due to an unorthodox method of treatment, the courts must determine whether the practitioner took account of all proper factors, and whether the departure was justified. It is important to stress at this point that normalisation is NOT a treatment, and cannot be used as such to prove negligence.

5 Duty to avoid economic loss. A practitioner must not make careless statements, including diagnosis and prognosis, which may cause financial loss to people.

6 Preserving treatment records. Actions for personal injuries may be brought by people up to three years after they have ceased to be affected by their mental disorder. Records should, then, be kept for a long time and consist of accurate information.

This mass of legal information may seem overwhelming to a mental health worker with little experience of the law. There are few rules actually laid down in the statute book, and most of the above advice has been inferred from case law. Workers in the community are perhaps more vulnerable than hospital workers, simply because there has been insufficient experience of community care from which case law can be derived. However, the lack of case law equally favours both staff and users. Many workers have very real concerns about legal accountability in the community, but it would seem that if working to a competent and professional standard, then they have little to fear with regard to being found negligent.

**Do consultants hold ultimate responsibility?**

The Nodder report(4) is quite clear on this point:

> **'There is, as we understand it, no basis in law for the commonly expressed idea that a consultant may be held responsible for negligence on the part of others simply because he is the "responsible medical officer"; or that, though personally blameless, he may be held accountable after the style of a military commander. A multi-disciplinary team has no "commander" in this sense.'**

What has commonly happened is that consultant psychiatrists have assumed prime responsibility. This may be appropriate in other fields where it is clearly established that one profession has an encompassing knowledge and understanding of the care group.(5) However, few would claim that psychiatrists have all the answers in caring for and helping people in mental distress, and it would seem inappropriate for any discipline to assume primacy in this field.

### Conclusion

Individual workers cannot escape confronting the issue of responsibility and accountability, but to do so can be a painful process, causing anxiety and uncertainty, which may lead to constraints on the delivery of care and the service being offered. Workers, then, need expert knowledge and the opportunity to discuss these issues in their teams; they require support from other workers so as to work creatively and with commitment. There is a danger that excessive concern with accountability may lead to a restricted and defensive form of care, this would be as much an abrogation of responsibility to users as other negligent practices.

Equally the fear of legal reprisal can hinder staff feeling confident and competent at working in the community. This is indeed an area of uncertainty and anxiety, although staff are afforded protection in law. They may like to have the position clarified by calling in a legal expert to discuss these matters.

## Staff Training

### Worries about new ways of working

Staff who have been based in institutions or psychiatric units cannot just go and 'work in the community'. Training is essential to help staff develop new skills, otherwise institutional habits and routines will simply be transferred from one setting to another.

Staff must be fully supported throughout their training. They may have many anxieties about their own abilities, and these must be handled sensitively and tactfully. The transition from a situation where staff feel skilled, competent and familiar (the hospital) to an unfamiliar environment where they feel deskilled and unsure of their role may be a difficult and unnerving experience. Staff should be encouraged and supported to tolerate the uncertainty and the anxiety; this can only be done if they feel they are getting adequate training and will not be required to practice new skills too soon.

In the context of this project paper, training involves a thorough understanding of the theory of normalisation, its relevance for mental health services, and the actual practice of this philosophy. The word philosophy is used advisedly; individuals will not just need to acquire a new set of practical skills but may have to think about their own personal values and the wider issues of commonly-held attitudes towards all devalued groups in our society. The aim of training is the development of staff competence in working with and helping people who use the service. This may require learning specific new skills (for example, anxiety management). It should also include aspects such as looking at the staff-user relationship, working to equalise that relationship and so empower the people whom the service purports to help. In this sense, training will be a continuous long-term activity. Staff will need supervision, peer support and positive monitoring of their work if they are to change existing patterns of service delivery. The training described above is aimed at promoting a standard of excellence through the technical and personel development of individual staff.

To maintain this standard, training should also stimulate the desire to try innovative and creative approaches in work. Managers must ensure that such approaches are positively encouraged and not criticised if they fail. Clearly staff should have the skills to evaluate and critically assess their work, and this should be promoted as part of their normal daily routine.

Training that has previously focused on particular professional skills, such as social work training or the nursing process, may no longer be the most appropriate approach. Training of this kind maintains professional boundaries and perpetuates the mystique of professional skills. It may lead to a sense of professional elitism with volunteers being seen as 'second class workers' and users considered hardly credible at all. Certain knowledge and skills can become trapped within a certain discipline, inaccessible and unavailable to others working in the field. This would not seem the most effective or efficient use of resources.

Effective services in the community, then, demands a multidisciplinary and multi-agency teamwork approach. Training should jointly involve health and local authorities, relevant voluntary agencies and service users.

## Training strategies

Training is a major undertaking. There are implications not only for finances and staff resources, but for the design and delivery of services. There needs to be a communication between staff who, through training, will change the delivery of services which will, in turn, inform new training needs. Working through the principles of normalisation will in itself change established practices. Training in normalisation can be a principal vehicle with which to effect change.

Training strategies need to be flexible and dynamic. Users should be involved wherever possible; they have a unique knowledge of the service and have much to teach staff. Staff, too, have valuable information about a service, this should be acknowledged and used when possible. Training strategies should be developed at every level from region through to individual projects. They should be developed as a coherent whole, with a unifying philosophy and overall sense of direction.(6)

## Building up community teams

The process of team development should be fully explored. Whether staff remain in an existing team that is transferred to the community, or belong to new teams, the process of forming a 'we' identity is crucial in determining the character of the working environment. Training is the ideal time to focus upon the nature of the team and explore the experience of being a team member. A cohesive team provides mutual support, fosters work of high quality and maintains morale. The phases of team development are well-documented. Shearer(7), summarises the process thus:

> 'First, people get to know each other and welcome each other into the team ("inclusion"), but there is as yet no sense of "we". Some people will put on a very sociable face; others will withdraw, and all may feel slightly uneasy. Then there is the development of group norms and competition for air space and power and the gradual development of roles. This phase can be tense or openly hositle, and people often feel irritated, defensive or paranoid. Finally, the team settles down, is relaxed, affectionate and quite cohesive, with a sense of "we", of flow and working together. Some teams will develop a creative challenging and risk-taking climate. Others will be oriented to stability and safety, with responsibilty placed with the leader, "them" or "the government". Reaction varies between these poles and depends partly on the task, the leadership and the members themselves. It's worth noting that while new members of the team have to go through these stages with the group, leaving members go through them in reverse order.'

**Conclusion**

This brief attempt to tackle the major issue of staff training and team development can do little more than sketch out a few pointers. Historically the emphasis in training has been on skill acquisition. However, if mental health services are to be more than an 'efficient mechanical contrivance'(8) then staff must possess more than mere competence to do their work. A new service demands new ways of working. Training needs to be creative and flexible and may well be the pivot around which a responsive and comprehensive community service will develop.

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