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Discussion Paper

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Collaboration for Change

**Partnership between Service Users, Planners and
Managers of Mental Health Services**

Helen Smith
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Tel: 01 267 6111

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Preface

This Discussion Document is the result of a group that has been meeting regularly to discuss issues around collaboration in mental health services. The members of the group are largely concerned in their own work to facilitate collaboration between health and local authorities, voluntary organisations and user groups. The difficulties associated with joint planning for community care was the motivation for forming the group. This focus has remained throughout our work together, but our understanding of collaboration has come to encompass many ideas from outside the mental health field.

This document has been written to share some of the work of the group and to get feedback from others interested in these issues. The form of a Discussion Document was chosen advisedly as we intend this to be used as a stimulus for further discussion and debate. There are no definitive answers in the pages that follow on how to collaborate with people who use mental health services, but there are suggestions, ideas and we hope, talking points.

Members of the group are:

Tim Dartington	National Council for Voluntary Organisations
Fabian Davis	Waltham Forest Health Authority
Ian Gregory	Coalition for Community Care
Chris Halford	Good Practices in Mental Health
Christina Murphy	Good Practices in Mental Health
Helen Smith	King's Fund Centre
Catherine Thomson	National Council for Voluntary Organisations

COLLABORATION FOR CHANGE

Introduction

This document will look at collaboration in mental health services between service providers and service users, although a lot of what follows will be of interest to all groups involved in collaborative ventures. There are two components in the process of collaboration; firstly, users themselves need to work together to find a collective voice and, secondly, staff need to be enabled to hear and act upon what users are saying. This document then, is not about "how to do" self advocacy, but about how staff can look to their own attitudes and working practices to ensure good and effective collaboration with service users.

There is often confusion around the notions of collaboration, participation and advocacy and it might be useful at this stage to define our terms more clearly. Self-advocacy is the assertion of wishes and rights by an individual, their expression of their needs and concerns. This country has seen a recent growth in the self advocacy movement. User groups in both mental illness services (see later) and mental handicap services (eg. People First⁽¹⁾), have become established as users have started to collectively speak out for themselves. Citizen advocacy is where someone unable to speak for themselves has a representative who speaks and acts on their behalf.

Citizen advocacy is more established in mental handicap services with, for example, projects such as the National Citizen Advocacy Project⁽²⁾. Legal advocacy involves advice on legal and welfare matters and representation to the Mental Health Review Tribunal. The Mapperley Advice Project⁽³⁾ and the Advice and Legal Representation Project at Springfield Hospital⁽⁴⁾ are examples of legal advocacy. Advocacy of any kind should not be confused with participation and collaboration, although the development of advocacy will almost certainly facilitate such activities.

We have taken participation to mean a term which applies to the overall field of user involvement in mental health services. Its literal meaning of "sharing in common" or "partnership" has many implications in practice. For instance, participation might take

place at the user/practitioner level, that is, at the point of service delivery. Participation at this level will probably be therapeutic in nature. Participation could also occur in the management of services and also at the level of planning and development of services.

The term **collaboration** has an equally wide remit in its translation as "cooperation" or "working in conjunction with others". However, we have defined it in this document as meaning collaboration between statutory agencies, voluntary organisations and user groups in the joint planning of mental health services. We have chosen this focus as it is currently receiving much interest within the mental health service. We have not though, focused just on planning; a lot of what follows equally applies to user involvement in managing and evaluating services.

This Discussion Document then, will reflect on why and in what way mental health services should actively seek to involve users, so as to offer a comprehensive and appropriate service.

* * * * *

CHAPTER 1

Participation - Past and Present

The move towards involving users in the planning and delivery of services reflects an established trend in the social policy field towards greater user participation. Throughout the seventies events such as the setting up of CHCs in the 1974 NHS reorganisation; the 1971 Seebohm Report on Social Service Departments; the Taylor Committee on School Governing Boards and the DOE report on Housing Tenancy in the same year, all proposed greater user involvement. In the health service the Griffiths Report in 1982 firmly placed consumerism centre-stage. The 1986 Cumberledge report on community nursing has more recently recognised this position. Participation in mental health services was advocated in the DHSS Draft Circular⁽⁵⁾, one of the most innovative suggestions to emerge from this particular development has been the recognition that service users have an essential contribution to service planning. The Circular states clearly 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 Disabled Persons Act (1986), sponsored by Tom Clarke, supported these developments by formalising advocacy for people with disabilities.

However, the welfare state, with no living history of either participation or consumerism until recently, has not sought to actively involve users in decision-making processes. The difficulties of introducing the practice of participation in "expert-led" services has led to user involvement often being tokenistic or non-existent. There are examples where users actively participate in the decision-making processes (eg. Chesterfield Community Mental Health Centre), but the dissemination and take-up of these ideas has been minimal. As Richardson⁽⁶⁾ notes, the pattern of planning services has traditionally been the identification by experts of the most effective policies for meeting what they consider to be people's needs. The

assumption that users have little interest in this process, leaving it to experts to ensure they are well served, is a hard myth to destroy.

Other historical factors militating against user involvement have been defined by Webb and Hobdell(7) as the "authority of position" and the "authority of knowledge". The authority of position is the professional and bureaucratic hierarchies that have historically shaped welfare services and the health service in particular. Authority of knowledge is the organisational principle enshrined in the professions; that is, a body of knowledge has come to belong to particular professions which require a specified length of training to master and possess it, before an individual can be seen as making a legitimate contribution within the service system. Position in the hierarchy and knowledge are closely linked and given authority and legitimacy by the ideology of an "expert-led" service. Indeed, for the health service to operate in the way it was originally set up, position and knowledge would have to go hand-in-hand, otherwise how could planners and managers justify "knowing best"?

The consequences for the person using the health service was that any contribution they might make was neither authorised nor legitimated by the system. Participation where it did exist was little more than lip service to an idea, as the underlying ideology and decision-making structures were never really tackled. However, within this system were the seeds of its own destruction. Dissatisfaction with the direction and form of the health service grew and became identified as a political issue. The limits of the old "bureaucratic paternalism" forced alternative strategies of reform into the limelight, characterised by privatisation or public provision solutions(8).

The Political Spectrum

One of the major problems in establishing participative structures in any organisation is the different meanings of participation reflected in the different political and philosophical approaches. Demands for reform in the health service have ranged in their nature between the right/left extremes of the political spectrum. The major ideological stances of this spectrum are briefly outlined below.

A non-market critique is based on a view of the welfare state as an oppressive and dehumanising system. Whereas services are needed by people, they are offered in a way that disempowers the user and thus maintains the status quo. Participation in this sense would involve a large scale transfer of resources and control of those resources to the local community. The social democratic lobby based on a commitment to "welfare pluralism", believes that the traditional welfare service has become financially and bureaucratically untenable. This approach looks to a model of services focusing on decentralization and increasing voluntarism. Participation becomes a central plank as people influence their own local services through the development of patch locality planning and the increase in voluntary organisations⁽⁹⁾.

At a further point along the spectrum an analysis of the welfare state from a market-based perspective sees the all-embracing nature of the state as being in direct conflict with individual choice and market-place competition. Efficiency is stimulated by the fact of commercial viability. Participation is seen to mean freedom to choose the type of service when you want and how you want.

Participation then, has become a more prominent issue at least in political and philosophical circles, largely in response to growing disenchantment with the current welfare state. However, as Beresford noted in 1981, "for all the interest in public participation, hardly any seems to exist"⁽¹⁰⁾. Sadly, six years later this is still true for mental health services and, one suspects, for other areas of the welfare state.

Participation in Practice

Clearly one of the major reasons for the virtual non-appearance of participation in practice in the social policy field is the absence of a single ideological message; and the fact that even within a particular school of thought, participation remains an elusive concept. As Maxwell and Weaver⁽¹¹⁾ have noted, the variables determining the degree of public participation are:

1. the nature of the service
2. the nature of the client group
3. the nature of the provider organisations

The interaction of these relevant factors at local and national level and all stops in between is difficult enough. Add to this the political interplay and the definition of participation becomes almost an individual affair, ranging from public consultation and consumer protection to planning and management of service delivery by service users.

The current situation within the user movement reflects the diversity of political approaches and the lack of an overall message:

- * Some groups are advocating user-run services and feel their experience of the psychiatric system as being one of disempowerment and restriction of rights. A response to this system means tackling the imbalance of power between service users and service providers by increasing user control over resources.
- * Other user groups are asking for involvement in monitoring services, training workers and representation in planning; seeking to influence services at a local level, they are not concerned to be directly involved in managing services. Nottingham Patients Council Support Group⁽¹²⁾, a group of users and ex-users, have been involved locally and nationally in training events for staff. The Council works to instigate user-only meetings in wards, day centres and community mental health centres and will support such groups in taking up issues with staff and management. The Council has also established working relationships with the health authority and influences the planning and management of the mental health services.
- * Some user groups are asking for changes not directly related to deficiencies in the health system, such as higher benefits or better employment opportunities.
- * Other groups still, are asking only for better services provided by the psychiatric system such as improved out-patient facilities; or see their role as supporting other users within an advocacy framework. The Resettlement Support Group⁽¹³⁾ based in North Manchester is a user group which offers support to people who are being resettled into the community. The group initially met at the request of Harperhey Resettlement Team, who

wished to discuss their plans with people who had first-hand experience of living in hospital, moving out, and living outside. Thereafter the group continued to meet and opened up membership to anyone who uses psychiatric services. User groups such as Womankind⁽¹⁴⁾ and the Afro-Caribbean Mental Health Association⁽¹⁵⁾ seek to provide a service, including an advocacy service to specific groups of users; in this instance women and afro-caribbean people respectively.

Even within the relatively narrow field of joint planning between health and social services there are different definitions of collaboration. These are based largely, as we shall see below, on what the planning team perceives to be its remit and objectives. Diversity is not a bad thing and indeed should be supported and encouraged. However, when engaging in collaboration it would seem useful to have a sense of the nature of potential political and philosophical differences and to be clear about what the other parties mean by collaboration. This requires understanding the collaborative venture within a wider conceptual framework; we will be suggesting such a framework below.

Is Consumerism Participation?

The major initiative from the State on the issue of participation has been the notion of consumerism. Promoted by Griffiths the supermarket metaphor now has the consumer taking their shopping trolley around the health service. On the surface this analogy would seem appropriate for mental health services, offering the consumers choice and control in the services they receive. However, in a rush of enthusiasm to embrace consumerism, the actual degree of participation being offered may be overlooked.

If we look further at the supermarket analogy there are a number of significant discrepancies that militate against its use for mental health services. Firstly, there are practical problems; people know where to find the local supermarket, know what it will look like inside and what to expect when shopping there. In contrast, finding appropriate services in a district can be a difficult task for the uninitiated. People have to rely on others, usually the G.P., to guide them on what services they need. Already there is a powerful intervening force between the consumer and his or her goods.

In a supermarket, shop assistants are there as helpers only, they will not interpret behaviour, restrict access to certain goods or actually compulsorily detain people. To assume that professionals are merely helpers and distributors of services denies the reality of the relationship between service providers and users. This relationship is based on the interpretation of an individual's experiences within a professional framework, be it medical, social or psychological. Equally, service development is not based on a model of consumer-driven market forces, but, as we have seen above, on what professionals wish to provide according to how they understand the problem. A solely market-led development of services would create a deep philosophical split within the current structure of the N.H.S. As Maxwell and Weaver⁽¹⁶⁾ have succinctly stated:

"The whole justification for its (NHS) existence lies in the rejection of the market principle as inappropriate for the organisation of health care. It is this which, in a sense, gives moral legitimacy to the paternalism of the providers".

This would, indeed, seem a dilemma; the drive for greater participation largely arose from dissatisfaction with the paternalism of the existing NHS structure. Yet consumerism would lead to questioning whether the NHS should exist at all. A radical extension of consumerism would mean no role for an expert body of knowledge in service planning, as distinct from consumer demands. These far-reaching implications are far from the spirit of participation embodied in the recent move towards user involvement in mental health services.

The dilemma is though, a false one and further highlights the necessity for genuine participation. Consumerism does not, in fact, need participation as a necessary condition. Winkler⁽¹⁷⁾ in her excellent article on consumerism in health care, states that:

"The supermarket vision of customer relations extends to reducing the waits at the check-out counter and exchanging faulty goods with the minimum of questions asked. It does not extend, even at Marks and Spencers, to inviting the customers on to the board, nor to consulting them about investment or even about what should be on the shelves, let

alone in their products. The supermarket concept certainly does not mean that retailers help customers sue manufacturers of products that have caused harm".

Consumerism then, as it is currently being promoted would not bring about major changes being more about "the appearance, not substance, of change".(18) Consumerism does imply choice in deciding whether to "buy" or not, but true participation as we originally defined it, that is, partnership and sharing in common, does not necessarily follow.

Where does this leave the notion of collaborating with people who use mental health services? Despite a common base for promoting participation (that is, a wish for a more responsive service) the many initiatives are clashing ideologically and politically, and making few inroads into real policy decisions and service planning. Perhaps we need to return to the basic starting point and look behind the assumption that users should indeed, be involved.

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CHAPTER 2

Collaboration - why do it?

One of the most powerful arguments for user involvement in human terms is that people with a mental illness have the same rights and, as far as possible, the same responsibilities as non-disabled people. This includes the right to self-determination and to influence and shape the services they receive. Whereas this argument is relevant for all health services, it is particularly so for priority services which may have a significant impact on a persons life. Mental health services intervene not just at a medical level, but also at a social and psychological level, further supporting the argument for individual choice and control over these interventions. Infringement of an individuals' rights through non-consultation and limitation of responsibilities affects the rights and dignity of each ordinary citizen.

Ethical reasons however, may not be the most persuasive argument in a health service coping with increasing cutbacks and growing financial constraints. One of the most powerful reasons for involving users in this situation is to ensure an effective and efficient service. How can managers be sure that services are relevant to peoples' needs unless they involve users in planning those services?

How can mental health workers assess the quality of their work unless they seek the views of those affected by their work? The mental health field is not one where experts know best. There is no single body of knowledge that informs the service and many different theoretical and practical perspectives are employed to help an individual. Feedback from the point of service delivery is essential to ensure that the individual is benefiting from what is being offered.

There are also what can be loosely termed "therapeutic" reasons for involving people in planning and determining the services they receive. The experience of mental illness is largely characterised as loss of control, over one's mental state, one's environment, over one's freedom if sectioned under the Mental Health Act. If contact

with mental health workers further limits or prevents people gaining control over their lives, then it challenges the legitimacy of the service.(19) In seeking to help people re-establish control over their lives, the relationships with workers will be vital in promoting a sense of worth and competence.

The growing reality of community care will highlight further the need to involve users in facing the challenge of the transition to community based services. To avert what may be a crisis in care we must recognize and use one of the service's most important resources so as to offer a comprehensive and appropriate service.

Structure of Collaboration

We have looked at why the demand for participation in the health service developed and, more specifically, why mental health services need to involve service users. As we have seen though, there are many different types of participation and it can help cut through the confusion if providers and users are clear about the activity in which they are engaged. We would like to briefly present a framework which maps out the structure of participation. Collaboration in joint planning of services is a part of this overall structure.

Windle and Cibulka(20) have defined three dimensions that provide a framework for understanding different forms and degrees of participation. This framework can be used to ask questions about the nature of participative activities.

The three dimensions are briefly described below:

1. Power Dimension

This dimension has three major levels:

- (a) Citizen Power:
 - * user control over services
 - * delegated power
 - * partnership between service providers and service users

- (b) Tokenism: * placation
 * consultation of users over
 plans etc.
 * informing users about plans
- (c) Non-participation: * therapy
 * manipulation through
 professional power

This dimension provides an interesting way of analysing participative ventures. If claims are being made for the exercise of power by service users, then the extent to which power is being truly shared can be assessed by using the above categories. Tokenism and non-participation are alright as long as both sides are clear as to the type of interaction that is occurring and the implications for the balance of power.

2. Participant Dimension

This dimension has four categories:

- (a) **Communities** (including voluntary organisations)
- (b) **Lay public**
- (c) **Service users**
- (d) **Professionals/workers**

This dimension shifts to look at participants and refers to the major groups of stakeholders in the service. These categories of participants will, of course, overlap and the internal composition will change. Much discussion about participation is concerned with how representative people are of their group. However, it must be said that this discussion is usually focused on user groups, professionals are rarely questioned about their representativeness. Most user groups though, are mostly clear about who they represent. A user group from the community mental health centre will not represent the views of elderly people on long stay wards and would not see it as appropriate for them to be involved in discussions about that particular service. National groups such as British Network for Alternatives to Psychiatry⁽²¹⁾ have always stressed that its members can state their experiences as individuals, not as representatives of "users" as a single group.

There is a danger that participation may become an elitist activity, despite its challenge to professional elitism and will attract people seeking power on an individual basis and not for the group they represent. Identification then, of participants is an important task if true representation is sought both within a group of participants and across the relevant groups of stakeholders.

3. Functional Dimension

Participation can be approached as a problem of different functions; that is, various policy stages can be distinguished thus:

- (a) **Authorising** - the legitimisation of a service development or programme through support and mandate of the groups of stakeholders.
- (b) **Enabling** - the funding and resourcing of participative activities.
- (c) **Planning** - This function is concerned with planning services and is where we have focused on collaboration taking place.
- (d) **Managing** - involvement in the management of services.
- (e) **Service giving** - the delivery of services.
- (f) **Evaluating** - research, service monitoring, peer review etc.

Involvement by service users can occur in one, some, or all of these functions, but the involvement will be quite different in each domain. It is essential therefore, that any participative activity is clear about the function being undertaken.

This framework provides a way of clarifying who is involved in what, and the nature of the activity. Collaboration in joint planning should aim to be a partnership between service providers, service users and other relevant stakeholders in the planning of mental health services. However, once the structure is established, how does collaboration then proceed? Below we will look at the processes that a collaborative group may engage in to address the task of joint planning.

The Process of Collaboration

In developing a model of collaboration it was necessary to look outside the health service for ideas. Other sectors in society have noted the growing need to promote collaborative problem-solving between different organisations eg. businesses, communities, government etc.

Gray⁽²²⁾ has devised one model of collaboration dependent upon the links between stakeholders and across agencies. This contrasts with the usual model of collaboration which focuses on the organisational structure of a single agency.

Gray's model would seem an appropriate way to approach user involvement, which, of necessity, involves different groups of stakeholders and different agencies.

This is a process model of collaboration and is based on the assumption that all stakeholders in the collaborative process are truly interdependent. This issue of interdependence has become largely invisible out in the field, (many professionals could well be reminded of their interdependence on service users, without whom they would not have a job!); different agencies may also like to reflect on their interdependence with each other. Keeping in mind the over-riding goal of providing an effective mental health service can help agencies view themselves as part of an inter-locking system - this recognition is often the initiating factor for collaboration.

Three major developmental phases are defined in establishing collaboration; we will look at these phases and in particular their relevance to the mental health service.

1. Getting Going - Identification of Stakeholders

This first phase is concerned with the identification of the stakeholders and their respective positions. This may not be an easy task, some stakeholders may not see the issues being considered as a priority, some may be indifferent, some may not acknowledge the need to collaborate. The stakeholders will change over time, depending upon the issues being considered. Identification, therefore, of relevant stakeholders is an ongoing process.

Before stakeholders can truly collaborate they have to believe in the positive outcome of such a venture. Incentives may need to be offered to some parties in terms of "pay-offs" for collaborating. Cultural norms supporting collaboration are a powerful incentive and management have a vital role in establishing such a culture. Critical to this initial process is, as mentioned above, the recognition by each stakeholder that their actions are inextricably linked with the others. Legitimacy is also crucial. Stakeholders have to recognise the perceived right and capacity of each other to participate.

In joint planning it is up to committed individuals to argue for the legitimacy and interdependence of stakeholders traditionally excluded from the planning process, such as users, their families, voluntary organisations. Initiatives such as the Draft Circular on joint planning start to establish cultural norms which may bring pressure to bear on the intransigent, but it will undoubtedly be a challenging task. Legitimacy is clearly linked to power, and those with little perceived power may need to work on increasing their power base before gaining legitimate status as a stakeholder.

User groups should look to building coalitions to support their position; sympathetic stakeholders who are in a more powerful position should develop their role as advocate for less powerful groups. Who initiates collaboration has a critical impact on its success or failure. A relatively powerful stakeholder is probably the best convener, such as the health or local authority. However, in cases of extreme conflict a neutral third party may be more successful, such as a voluntary organisation. This latter approach has given rise to reticulists, people whose job it is to bring agencies and people together to collaborate.

The Lambeth Forum⁽²³⁾ is such an example whereby a development worker from an independent organisation (Good Practices in Mental Health), set up a forum which included health and social services, voluntary and community groups, user groups, GPs and other individuals with an involvement or interest in mental health. The aims of the Forum have been to monitor and evaluate service provision in Lambeth and to make comments and recommendations to planners and policy-makers. Coalition for Community Care operates similarly in Westminster, Kensington and Chelsea.

In summary, during this initial problem-solving phase, stakeholders are identified and legitimized, interdependence is recognised, preliminary expectations established and the boundary of the collaborative venture defined.

2. Mapping out the Work - Direction Setting

One of the major tasks in the second phase is to establish the values that will guide the work of the collaborative group and set overall directions for the group to pursue. This may take considerable time and effort, but is vital to the future work of the group.

Problem-solving is best facilitated by recourse to a superordinate goal which embodies the shared values of everyone; in joint planning this would be offering an effective comprehensive service for people in mental distress. Values, attitudes and expectations about the task in hand need to be openly discussed and commonly agreed upon. For example, in planning ordinary housing for people discharged from psychiatric hospitals, the group's shared values might be a belief that people with a mental illness have equal human rights and therefore a right to ordinary, high quality housing. Establishing these shared values helps create a path to follow through the pitfalls and challenges that will occur in the planning process. The involvement of users is essential to base what might be abstract discussions in the day-to-day existence of people with a mental illness.

Another major challenge in setting the directions of the group is again the difference in power between the stakeholders, some of whom will have greater control over critical resources than others. Users will probably have no control at all over resources. Some balancing up of power is necessary for continued joint work, and to ensure that directions are not skewed by the interest of those with greater power. An effective argument to stronger groups to disperse their control over resources is again the recognition of interdependence; also the recognition that sharing will stimulate creativity and that combined efforts are greater than the sum of individual (often conflicting) efforts.

An example of this is the multi-agency Community Dementia Team which operates out of Guy's Hospital. The consultant gave up her power of admission and discharge to hospital beds over to the Community Dementia Team. The local authority gave their power over admission to Part III Homes to the team. Clearly defined management of individuals and resources through a key worker system ensured that referrals were not 'lost'. This considerable dispersal of power resulted in a more effective and efficient service to people with dementia and increased the ability of each agency to deal with the problem. This innovative and courageous step is to be applauded in a field often fraught with conflict over territorial rights of access.

Once the group has defined common values and looked to a more equal dispersal of power within itself, then the positive benefits of collaboration will start to show. However, the collaborative activities need to be formally regulated to continue working. This third phase involves structuring the group, formally and informally, so that it develops a life of its own over and above the participants.

3. Working into the Future - Structuring

The changes that will have occurred in the group as a result of the previous phases need to be continued. The primary motivation for continuing joint working will be if stakeholders continue to perceive their interdependence. This is important if the group is to follow its set directions and achieve its goals.

A formal structure is usually established with assigned roles and responsibilities to ensure the implementation of action by those at a more senior level in the relevant agencies. There is a danger that during the structuring phase, people who use services will become marginalised and left without any real role in the ongoing work of the group, (are users, for instance, elected as secretaries/chairs to the group?). Genuine collaboration means equal access to positions within the group.

* * * * *

CHAPTER 3

We have briefly looked at the collaborative process with particular reference to service users collaborating with planners and managers, although the process we have described is probably universal. This is a complex area and merely describing the process does not do justice to the tangled web of attitudes and expectations that everyone brings with them to a meeting and the personal and professional history that will influence their interaction with others.

Blocks to Collaboration

The taken-for-granted world can make it especially hard for service providers to collaborate with users. Firstly, the term "user" is good on philosophy but short on realism as it rarely reflects the way mental health workers think or talk about users. More often users are thought of as patients, with connotations of suffering and passivity. Social workers describe them as clients which is a valued term in other instances (eg. solicitors), yet does not imply equality in this particular relationship.

Years of training and the use of a professional language construct service providers views of their world. Professional training builds up a web of myths, illusions and attitudes that may form a smokescreen to obscure what really happens between service providers and users. The effect of hidden meanings and assumptions embodied in being a professional worker means that contact with people who use the service is interpreted and translated to fit into a framework, be it a medical, social or psychological framework. How then, do we make sure that what users say is not lost in professional translation? How also, do we enable staff to hear something not delivered in a professional language?

User groups in this country are seeking to understand their own experience in social and political terms. What this means for service providers is that they must look to the unconscious, pervasive attitudes and values that society has towards people with disabilities and which they themselves may be influenced by. The prejudice towards people with a mental illness that is often portrayed by, for example, the media, is also more subtly and covertly reflected in those

services that project a stigmatising and negative image of people who use them.⁽²⁴⁾ Effective collaboration with users will not occur until mental health workers rigorously challenge and question their own assumptions and expectations of people with mental illness.

Disability awareness is about realising that we have all been exposed to stereotyped and negative views of disabilities and we may handicap and restrict the people who use services in ways we do not immediately recognise.

Practical Ways of Facilitating Collaboration

1. Resourcing User Groups

For users to participate as representatives of a group of people they need access to funds, rooms, a photocopier, secretarial support and so on. If collaboration is seen to be of value it must be adequately funded and resourced. Do user groups have the opportunity of using the boardroom for their meetings? Are they also served refreshments? How do workers facilitate collaboration between users so they can in turn, collaborate effectively within the system? A community work approach linking users with each other may be an important first step in aiding collaboration.

2. Sharing Information

User groups will need information about the complexities of the NHS. The structure alone is difficult enough to understand, but users also need political knowledge about how the bureaucracy operates. Workers joining an established department have access to informal knowledge about allies and "hot spots" within the district. This local information is important, and user groups should initially be helped to "work the system". The emphasis though, should be less on educating users to collaborate with professionals and more on changing the structures and processes to make them accessible.

Brandon and Brandon⁽²⁵⁾ in looking at the development of participation in mental health services note the importance of users receiving information. They remark on the need to develop more effective systems for passing on information. This is an important point;

collaboration requires an equal sharing of information between all groups and a recognition by staff of the two-way nature of this process. People who use services have a vast reservoir of knowledge about the service and about mental illness in general. Workers and users need to look at ways of using this information to increase knowledge and understanding of mental illness.

Groups such as Camden Mental Health Consortium(26) have generated their own information through research into the major needs of people discharged from hospital. This survey of a significant number of users in Camden was done to identify their needs in the following areas: housing, financial stability, work opportunities, day care, social and leisure activities, medical after-care and support in crisis. Recommendations for service development were made arising from their findings.

3. Changing Working Relationships

Staff can facilitate collaboration by altering the pattern of service delivery to work "with" rather than "on" people(27). This change in working patterns will contribute to users feelings of worth and competence and aid the development of self-advocacy. Rose and Black(28) looking at an advocacy/empowerment approach in mental health work explore the changes in working relationships that would facilitate this approach. They challenge a psychiatric system that consistently "submerges" people, keeping them passive, acquiescent and devalued.

For example, the issue of confidentiality is important in that the status of workers is grounded in a position on confidentiality. Yet they continually breach this position, mostly without asking the individual, when liaising with other disciplines and agencies. Users know this happens, yet it is presented to them as necessary for their care and the coordination of services. Confidentiality then, is preserved as part of the caring relationship and broken for the same reason.

This double-bind situation 'submerges' users in that they become unable to challenge the breach of confidence if they wish to gain access to certain services. If workers are to change their

relationships with users, then they must clearly state the rules by which they are playing. So, where confidentiality is concerned, it is made clear when and what information will be given without the users permission, when (written) permission will be sought, and what information will be strictly confidential to a particular worker or group of workers.

Communication with users should focus not just on the pathology itself (if at all), but on the effects of mental distress and practical ways of alleviating these effects. Workers may find this changes their work to include an awareness of housing, social security, welfare benefits, etc. We are not saying staff should become experts in these areas, but they must have a working knowledge of other welfare systems, most of which users will also be involved with.

Rose and Black state "It is our task to help make the thematic content of people's lives clear to them through the process of dialogue". Workers use their skills of critical reflection and their knowledge of the themes of mental distress, to arrive at an understanding with the individual of their problems. This process will help individuals look at common themes in their own lives, part of which will be their own mental distress, other parts will reflect the wider experience of alienation and powerlessness that many disadvantaged groups suffer. Staff must learn to work with what users are saying, not what they think they are saying.

4. Building Partnerships

Workers must beware of overwhelming newly formed user groups with demands to collaborate within the system. It may be that user groups will only ask for more information or to be consulted on certain issues. Staff, on the other hand, may feel less exploitative and good about their job if they involve users, and, in their enthusiasm, involve users inappropriately in their work.

Alternatively, staff may seek to subvert collaboration by inappropriately handing over decision making to people who are unprepared and not ready to take on this role. Users, like everyone else, need time and training to collaborate effectively. Staff must work with users to provide a structure within which to hand over

decision making at a pace set by service users, not staff. Staff must also beware of passing on day-to-day decisions to users, while keeping more major decisions to themselves.(29)

"Skills for People"(30) is a project which provides training for people with disabilities by helping them develop self-confidence and the skills necessary to be active members of meetings. The focus of the project is to enable people with disabilities to become co-planners, leaders of workshops and courses, committee members and so on. This support of users to work on an equal basis with others increases the extent to which users can make decisions and take control of their own lives.

User groups though, may view their best interests as being served through a campaigning as opposed to a participative role and so not want to become involved at all in collaborative ventures. This wish to remain 'outside' the system must be respected and may be a necessary first step in individuals and groups developing confidence and assertion skills. It may also be that a pressure group is felt to be the best way to promote users' interests and that involvement in health service structures is not the best way to bring about change.

5. Collaborating with people who are severely disabled

Involving users who through institutionalisation or mental distress find it difficult to articulate their needs and their opinions is a challenge for service providers. However, it is particularly important to confront this challenge in light of the closure of long-stay psychiatric hospitals and the resettlement of people in the community. It is essential to seek the opinions of these people to ensure that the service being developed in the community does, in fact, meet their needs and that they are enabled to make an informed choice about the options available to them.

Lambeth MIND(31) has been working with users on long-stay wards to discuss issues relevant to their move into the community. They have developed a simple game which aims to facilitate discussion on various aspects of housing. They have additionally assembled a set of slides and a large set of cards for use in hospital, to provide information to users and engage them in thinking about their future.

It may be however, that for a small number of people, normal channels of communication are not sufficient to fully express their needs. In these instances, approaches such as "Getting to Know You", pioneered by John O'Brien⁽³²⁾, may be useful. This approach involves detailed observation of an individual over a long period, including all parts of the 24 hour day. The observation is an active process and is the primary task in hand. A nurse working on the ward cannot do "Getting to Know You" as he or she is involved in other activities at the same time. Where possible it is preferable for an observer to have little or no knowledge of the individual prior to "Getting to Know You" so as to minimise their preconceptions of the person.

By building up an intimate picture of a persons life it is possible to infer their needs and the most preferred options for their future.

Another challenge that may have to be faced is collaborating with people in a state of mental distress, or who may be behaving significantly differently to other people in the room. Effective chairing would be the usual approach with people who wander off the point or bring up "red herrings"; equally, good chairing is necessary for people who do the same things for reasons of mental illness.

6. Training and Support

There needs to be some way of changing professional attitudes through education and training. Involving users in training programmes is an important first step in this process. We have mentioned above the work done in this area by the Nottingham Patients Council Support Group. Other user groups are also directly involved in training staff such as Glasgow Link⁽³³⁾ which has produced with ESCARTA a video-based training package for mental health workers.

Collaboration with users entails workers, planners and managers reshaping their practice and learning skills of dialogue and negotiation. This process can threaten people's professional identity and status and question the pre-determined framework which has guided them throughout their working life. This can be a liberating challenge for some, or a devastating experience for those with very fixed ideas about their work. Support for staff, therefore, is a necessary part of greater user involvement.

7. Challenging the prevailing ideology

We discussed above the constraints imposed on user involvement by the "authority of position" and the "authority of knowledge". The traditional linking together of position in the hospital hierarchy and the degree of knowledge that is publicly recognised has meant that users have never had legitimate access into the psychiatric system other than as patients. This organisational ideology needs to be challenged and replaced with "authority of relevance".⁽³⁴⁾ This would mean that legitimate access to decision-making processes of any kind would be dependent on the relevance of an individual's contribution to the particular issue being discussed, regardless of position or discipline. Clearly service users would have a large claim to be involved on these grounds.

Outcomes of Collaboration

Given the limited state of current knowledge and practice of collaboration there is little known about effectiveness and outcomes. There are numerous difficulties in evaluating participation as a whole given the complex nature of participation, politically and structurally. Also the impact may be felt at different levels in different ways. We are developing the conceptual tools to look at the structure and process of collaboration; at the moment this is helping to identify problems of implementation, hopefully it will soon also enable us to assess outcomes.

Collaborating into the Future?

The ideas of participation and collaboration are receiving more interest and changes in practice are slowly emerging. The rapid growth of user groups is evidence enough that users are responding to the notion of self-advocacy and, in most instances, service providers are equally willing to explore the possibilities.

The practical implications, however, still need to be addressed. What can users and practitioners do to improve levels, of collaboration and participation? A response might mean devising guidelines for service providers to help them collaborate better. It might also include ideas for users on how better to "work the system" and set up improved

arrangements for user involvement. Examples of good practice in this area need to be identified and learnt from.

These are exciting times for mental health services. The changes in patterns of service delivery associated with hospital closures and the emergence of new partnerships in planning and delivering care has opened up new possibilities for a truly responsive and effective service. Practitioners and users should grasp these possibilities together and ensure that future mental health services are needed and wanted by people who will use them.

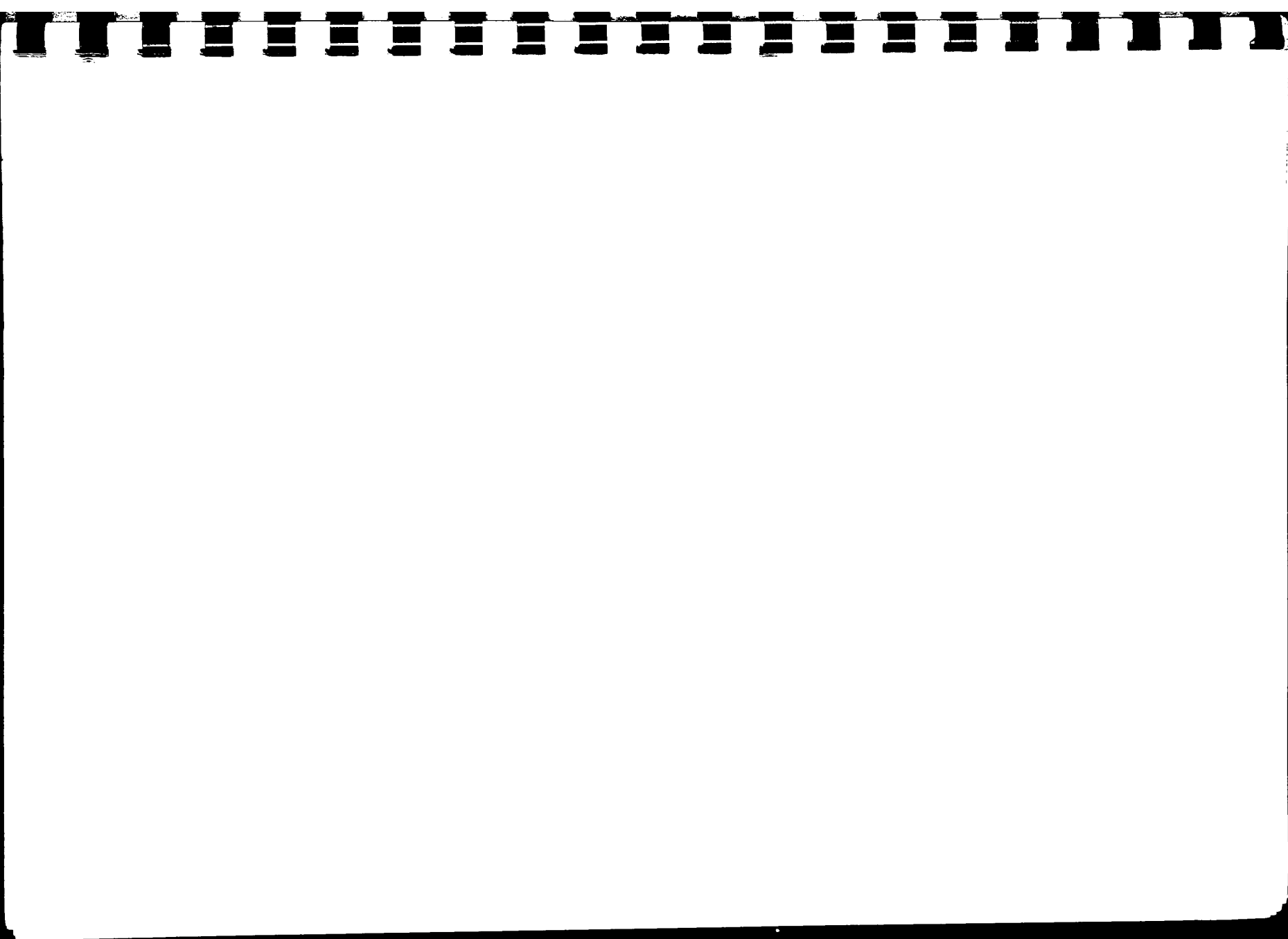
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