Consumer involvement in mind: a study of participation in a voluntary organisation for mental health

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DEDICATION

THIS THESIS IS DEDICATED TO:

THE MEMORY OF MY MOTHER, EILEEN BYRT; TO MY FATHER

AND SISTER

AND TO ALL OF US WHO HAVE EXPERIENCED MENTAL

HEALTH PROBLEMS.
SPECIAL ACKNOWLEDGEMENT OF SOURCES

My thanks to my research supervisors, Professor Adrian Webb and Mr Gerald Wistow, for their many suggestions, including several related to the wording of the text.

I have borne these suggestions in mind in the rewriting of the thesis. In general, I have paraphrased the written suggestions of my supervisors, but there are a few words or small parts of the text which are the same, or close to their wording.

Richard Byrt

November, 1993
# CONSUMER INVOLVEMENT IN MIND

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Richard Byrt
May 1993
CONSUMER INVOLVEMENT IN MIND

ABSTRACT

SYNOPSIS OF THESIS

The thesis is a study of consumer participation, focussing on a case study of MIND. Data were collected from interviewing, participant observation and examination of records. The following are the main conclusions.

In order to understand consumer participation, and effectively to increase it, it is necessary to be aware of: the different types of such involvement; the extent to which it includes opposition or collaboration with people in authority; the various types of participant; and the levels and degrees of participation. Levels vary from involvement in decisions about the individual's own care to Central Government policy making; whilst degrees of participation range from information to the total running of an organisation. Also important is the extent to which consumer participation is openly declared, conscious, and formal or informal. This was found to vary considerably within MIND.

MIND has its origins in a beneficent organisation, but from the nineteen seventies, increasing efforts were made to facilitate consumer participation. Almost all respondents were in favour of this, but there was considerable uncertainty about the most effective means to facilitate such involvement, and doubts about whether proposed policies for its implementation would be successful.
Respondents often mentioned psychological gains and the value of individuals' skills and abilities as benefits of consumer participation. However, difficulty in taking on responsibility was frequently said to result in problems. The attitudes and aptitudes of members with experience as consumers or mental health professionals, and the personal influence of National/Regional MIND staff, were seen as crucial in facilitating or hindering consumer participation, as were organisational factors such as the structure of meetings, the complexity of functions, and the relationship between different levels of MIND, which resembled Rhodes' description of central subcentral government relations. The influence of National/Regional MIND on Local Associations was limited because the latter were autonomous charities.

The thesis also covers methodological and ethical problems, and the implications of the finding for implementing policies to increase consumer participation in voluntary organisations.
INTRODUCTORY NOTE

This thesis is about consumer involvement in MIND, the largest voluntary organisation for mental health in the U.K. Most of the fieldwork for this study was undertaken between August, 1984 and October, 1985, during a three year research studentship from the Economic and Social Research Council. Analysis of data and writing the thesis took place from late 1985 to May 1993.

One reason for the long delay in the production of the thesis was the collection of a large amount of (mainly qualitative) material from participant observation, documents and over 200 semi-structured, and often in-depth, interviews. These data took considerable time to analyse and collate. The work for the thesis was completed part-time after the studentship ended in September, 1986. After this date the delay was caused principally by both work commitments and domestic upheavals, but also partly, it must be acknowledged, by poor time management.

The major part of the research, and of this thesis, remains, as was always proposed, a case study of one voluntary organisation at a particular period in its development. Since the mid eighties, however, both MIND and the policy context have moved on. A brief study of recent MIND literature suggests that consumer involvement has increased within the organisation, with developments such as the establishment of an active Consumer Advisory Network, and the election to National MIND's Advisory Network, and the election to National MIND's governing body, of people with consumer experience. In addition there has been a recent large increase in voluntary organisations run by consumers, and in "consumerism" in public services, including many assessments of patient and client satisfaction with Health and Social Services.
Although brief references are made to recent developments, the main aim of this thesis is to give a detailed analysis of consumer involvement in MIND in the mid eighties: a time when many individuals perceived a need for such participation within the organisation, and were searching for ways to increase this. The study is placed largely within the context of Central Government documents, and other literature on participation, which were current to the time.

The thesis aims to enhance understanding of the meaning, development and dimensions of such participation; resultant benefits and problems to individuals and to the organisation as a whole; and factors which facilitate and hinder the development of consumer involvement.

Richard Byrt

"Everyone is for participation, ... it can't be bad. But who is able to say what it is?" (1).

Since the early nineteen sixties there have been increased attempts in many industrialised countries to enable participation: the involvement of members of the public in decision making and responsibility in a variety of statutory and voluntary services (2).

The importance of "community participation", "citizen participation" and "consumer participation" or "consumer involvement" has often been stressed (3) and these terms usually refer respectively to the involvement of members of a local community, a town or city, and users of particular services (4).

Many authorities have commented that, despite the belief of many of its proponents that such involvement is a "good thing", there have been limited attempts to adequately define or conceptualise participation (5). Arnstein commented of citizen participation in the USA in the nineteen sixties that it was "...a little bit like eating spinach: no one is against it in principle because it is good for you... But there has been very little analysis of the content of "Citizen Participation"..." (6).
More recently, Richardson comments that, in the United Kingdom, participation has generated strong feelings in both its proponents and its critics but that "...little consensus has been reached about what participation actually does, for the new participants, or for anyone else." (7).

In the USA there was a movement in the nineteen sixties to increase participation in a variety of statutory services, particularly those concerned with the amelioration of poverty and discrimination (8). There has been less concern to increase such involvement in the UK, but the idea of participation has been given approval in a variety of Central Government reports and papers, and legislation has been passed to enable participation in environmental planning, the National Health Service, Social Services, Education and Housing (9).

The present research attempts to contribute to a better understanding of the meaning and nature of consumer participation in voluntary organisations for mental health. In statutory services for mental health in this country, participation appears to have been initiated largely by professionals, and to be confined mostly to decision making and responsibility in relation to individual treatment, and to psychiatric wards, hostels, day centres and social clubs. In contrast, from the early nineteen seventies, in both the USA and the UK, there has been an increasing number of voluntary organisations founded and run by people with experience of mental health problems, and a recent growth in interest in increasing consumer participation within MIND, the largest, and one of the oldest voluntary organisations for mental health in the UK (10).
The present research was undertaken because, whilst some people involved in mental health services see consumer participation as a "good thing", there appear to be few attempts to critically examine the meaning of the concept, or to determine the amount of consumer participation which is optimum for individuals or for organisations. My interest in consumer participation was influenced by my experiences as an outpatient "consumer" of psychotherapy, and as a psychiatric nurse, both in therapeutic communities where residents were encouraged to be involved in decision making and responsibility; and in other psychiatric units where decisions were often made on behalf of patients, with little consideration of their needs and wishes. These experiences spurred an interest in studying the contribution which consumers can make to mental health services and organisations as a result of their own experiences (11).

BEGINNING THE RESEARCH

The study, which began in October 1983, was intended to be linked to research at Loughborough University of Technology on central-local government relations. Originally, it was planned to relate this topic to the community care of people with mental illness. Much of the study was to have concerned the extent to which: a) Local and Central Government policies met the felt needs and wishes of people with mental illness; b) users of services were involved in relevant policy making and policy implementation at central, and particularly, local levels. However, initial thinking and reading brought questions related to the nature of consumer participation more to the fore. These included the
following: What does consumer participation mean? What are the levels and degrees of consumer participation? To what extent is consumer satisfaction with services related to consumer participation in policy making and policy implementation (12)? What is the role of pressure groups in influencing policies for services for people with mental illness? By early 1984, it was decided that consumer participation should be the topic of research. It was decided to study this in MIND, rather than in statutory services, for the following reasons:

1. Attendance at an open meeting held by a Local Association of MIND in October, 1983, and initial reading of MIND literature, indicated that the organisation was interested in consumer participation, and that participants might welcome a study in this area.

2. Access was felt to be easier, compared with Health Authorities and Social Services Departments.

3. MIND is the largest, and one of the oldest (13), non-statutory organisations in England and Wales which represent the interests and rights of users of mental health services. The nature and extent of consumer participation in an organisation which campaigns for consumers' rights seemed worthy of study in its own right. Some of the organisation's participants were skilled in advocacy and the representation of consumers' interests, and these activities constituted a substantial part of National MIND's work (14).
4. Finally, MIND was an interesting organisation precisely because, judging from its literature, its values and interests were supportive of consumer participation (15).

**MAIN TOPICS OF THIS STUDY**

The research has been mainly concerned with the following topics, each of which is considered in subsequent chapters.

1. Descriptive accounts of MIND and of issues of relevance to the study.

2. Conceptual analysis of consumer participation, with review of relevant literature, to enhance understanding of the meaning, characteristics, types and dimensions of consumer participation.

3. The representation of the interests of people with mental illness by voluntary movements for mental health since the late Eighteenth Century.

4. Ways in which MIND represented consumer interests and encouraged consumer participation from its inception in 1946, particularly during the period of fieldwork.

5. The extent and nature of consumer participation in local, regional and national levels of MIND during the period of fieldwork.
6. Reasons for the interest in increasing consumer participation in MIND.

7. The benefits and problems of consumer participation to: a) individuals so involved; b) the organisation as a whole.

8. Factors which facilitate and hinder consumer participation in MIND at local and national levels.

9. National - Regional - Local relations within MIND and their influence on consumer participation at different levels of the organisation.

10. The similarities and differences between MIND and voluntary organisations for mental health which are run by consumers.

The following were also examined, but are not considered in depth in this thesis.

11. MIND's contact with, and influence on, central government and local statutory services.

12. The extent to which people with consumer experience are involved in MIND's representation of consumer interests to Central Government and to local statutory authorities.
In the early stages of fieldwork, it was intended to study other topics. These included the influence of consumers' felt needs on statutory policies and services, consumer satisfaction with services, and the extent and nature of consumer participation in statutory organisations and services. It proved difficult to collect material on all these topics, and the research became focused on a detailed empirical study of consumer participation in MIND, set within a conceptual and historical framework. In addition, a small amount of material was collected on six voluntary organisations and trusts for mental health which were run largely or completely by people with experience, as consumers, of mental illness or mental health services, and/or their relatives: Depressives Anonymous (16), the Manic Depression Fellowship, the National Schizophrenia Fellowship, Campaign Against Psychiatric Oppression, the Matthew Trust and Orans's Trust.

**ACCESS TO MIND**

Access to MIND for the research was very readily agreed by the National Director in March 1984. At his suggestion, the author met occasionally during fieldwork with two Assistant Directors who agreed to additional topics of study, to the use of other research methods, and to the selection of various participants to approach for interview (17).

The main research methods used were:
1) Examination of documents in the National Office, a Regional Office and in two Local Associations. MIND publications, internal memoranda and minutes of meetings were analysed.

2) Participant observation, mainly in the National Office and in two local associations.

3) Interviewing, usually in-depth and semi-structured. Over two hundred interviews were conducted with users of local association services, other local association participants, members of National MIND's council of Management, National and Regional MIND staff and volunteers. Other interviewees included politicians and senior civil servants, mental health professionals in the towns served by the two local associations studied in depth, and members of the six other voluntary organisations for mental health which were studied (18).

In addition to the above methods, a small number of respondents was given brief structured self-completed questionnaires about specific topics. Non-participant observation was conducted in a few National and Local MIND meetings.

STAGES OF THE STUDY

In Stage 1 which lasted from August to November, 1984, an attempt was made to get an initial "feel" of the organisation and to get to know some of its participants. Explanations of the research were given. The author acted as a participant observer in the National Office, sometimes helping in the Community Development Department, answering phone queries.
and performing routine clerical tasks, and meeting volunteers and staff during coffee breaks. Literature and files on Local Associations were examined in both the National Office and in a Regional Office which I will call "Albion" (19). Pilot interviews were conducted with Albion Region staff, and a few Local Association participants, in an attempt to assess the degree, extent and nature of consumer participation in nine local associations in Albion Region. The Local Associations Co-ordinator in the Community Development Department was interviewed about Local Associations in England and Wales (20).

Stage 2, from November 1984 to May 1985, consisted of a detailed study of two Local Associations (Eastvale MIND and Westhill MIND) in Albion Region, which were chosen from the nine Local Associations studied in the pilot interviews. Eastvale MIND was chosen because, of the sample, it had the highest amount of consumer participation at Executive Committee level, and Westhill MIND because it was one of the Local Associations which had no consumers, but several mental health professionals, on its Executive Committee. (Westhill MIND was chosen in preference to other Local Associations with similar Executive Committees because it was more accessible, geographically.)

About twelve weeks was spent with each of these Local Associations undertaking participant observation in the centres, and non-participant observation in Executive Committee meetings. The participation included joining in conversation, social and recreational activities, helping with jobs in the centres and with fund raising activities, and listening to people in distress. It was only when I was fairly well known by
participants, that I began in-depth interviewing of Executive Committee members, staff employed by the Local Associations, users of their services and volunteers (21). Records of the two Local Associations were examined, particularly those of Westhill MIND. Interviews were also conducted with a small number of local mental health professionals who were not directly involved with MIND.

Stage 3 mainly from May to October (1985) (22), comprised in-depth interviewing of National and Regional MIND staff and volunteers, members of National MIND's Council of Management and Forum (a body consisting of Local Association representatives), and consumers in several Local Associations which were said by Regional Staff to have high levels of consumer participation. In order to understand the relationship between MIND and Central Government, eight senior civil servants were interviewed. Fifteen participants in six voluntary organisations for mental health which were founded and run by consumers and/or their relatives were also interviewed, so that a contrast could be made between MIND and such organisations. Four people involved in Dutch patients' rights groups were also interviewed.

ANALYSIS AND WRITING UP

The analysis of data and writing the thesis were undertaken between October 1985 and October, 1992, with final revisions being made between the latter date and May 1993. This long delay was caused by two factors:
1. Too much data was collected, including innumerable notes from about twenty weeks of participation observation, analysis of documents, and over 200 semi-structured and often in-depth interviews. A great deal of detailed and interesting data was collected but this took considerable time to analyse and collate. In retrospect the work undertaken was too ambitious. Methodological issues and problems are further considered in the next chapter.

2. The studentship from the Economic and Social Research Council ended in September, 1986; and subsequently, the analysis and writing up was completed part-time, whilst undertaking full-time work. In retrospect, poor organisation of time was another contributory factor to the delay in completion.

THE SCOPE OF THE THESIS

It is not intended to bring the research "up to date" by describing consumer involvement in MIND at present, although occasional brief references are made to more recent developments (23). Instead, much of this study consists of a fairly detailed analysis of consumer participation in MIND at a time, in the mid eighties, of increased interest in participation within the organisation, with attempts
to increase this at Headquarters, and in Regional offices and some Local Associations. Through an analysis of consumer participation during the period of fieldwork, and of literature on participation, including Central Government documents current at the time, an attempt has been made to better understand the meaning and components of consumer participation, the benefits and problems of such involvement, and factors which facilitate and hinder its implementation.

"CONSUMER PARTICIPATION" and "CONSUMER INVOLVEMENT".

Finally, a note on the use of "consumer participation" and "consumer involvement". This is considered in Chapter 3, where it is concluded that the two terms are synonymous (24). "Consumer participation" is more frequently used in the literature, but almost all MIND respondents referred to it as "consumer involvement". For this reason, in the rest of this thesis, the term "consumer participation" is used in reviews of the literature, whilst "consumer involvement" refers to participation in MIND. The next chapter includes a consideration of methodological and ethical issues related to the study.
This Chapter includes an examination of the main methods which were used in the research, and the ethical problems which were encountered.

METHODOLOGICAL TRIANGULATION

It was decided to use a variety of research methods, in order to obtain as detailed and complete a picture of MIND as possible. Denzin refers to the use of several research methods as Triangulation, and argues that this enables the social scientist to obtain a more accurate understanding of the social group or organisation than if just one method is used (1). A number of social scientists have argued that different methods complement each other and add to the researcher's understanding (2). For example, some social psychologists have commented that respondents' statements, in interviews and questionnaires about their attitudes and beliefs, may not be reflected in behaviour which is observed (3).

METHODS USED

The main methods used in the study were:

1. Examination of documents.
2. Participant observation.
In addition, a brief self-completed questionnaire was given to a few respondents to assess consumer involvement in Local Associations, as part of preliminary fieldwork. Non-participant observation was carried out in some meetings in National MIND, and in several Executive committee meetings in two Local Associations which were studied in depth.

Each of the methods used produced data which, on its own, yielded an incomplete picture. National MIND records on Local Associations were often incomplete, and gave little idea of the amount of consumer involvement which existed. Interviewing gave some indication of participants' stated beliefs about consumer involvement in Local Associations, but this did not necessarily indicate what happened in practice. The latter could, in some ways, be more accurately assessed through participant observation, but only a limited number of Associations could be observed because of the time-consuming nature of this method. Additional interviewing was needed to gain further information about consumer involvement at local level.

**RESEARCH UNDERTAKEN**

Chapter 1 includes an outline of the research which was undertaken (4). Preliminary fieldwork consisted of participant observation in the National office, initial interviews of staff at Headquarters, a Regional Director, and Local Associations in one MIND Region. In addition, documents in the National and Regional offices were examined.
Later research comprised participant observation in two Local Associations (Eastvale and Westhill MIND), further examination of documents, and (mainly in-depth) interviewing of participants at all levels of the organisation. In addition, interviews were conducted with members of six other voluntary organisations for mental health; and with professionals in the towns of Eastvale and Westhill, senior civil servants in the then Department of Health and Social Security, and a few politicians.

Each of the main methods used will now be considered in turn.

1. **EXAMINATION OF DOCUMENTS.**

Records such as Annual Reports were useful because they were the "public face" of MIND: the officially stated aims and objectives, including those related to consumer involvement; but they said little about the variety of views held by participants at different levels of the organisation, or how far consumer involvement actually existed. (Such documents were not, of course, written with such purposes in mind). Local Association records, such as minutes of meetings, also rarely indicated the extent of consumer involvement.

Gaps in information from records were, in some ways a problem: e.g. in gaining an initial impression of the amount of consumer involvement in Local Associations. However, these gaps told me something about the organisation. Incomplete records and National/Regional MIND staff's lack of knowledge of the extent of consumer involvement in particular Local Associations indicated the latter's high degree of autonomy from other
levels of the organisation, and led to the formulation of questions and ideas: e.g. that Regional MIND's attempts to influence consumer involvement in Local Associations would be likely to have little effect because of their autonomy.

2. PARTICIPANT OBSERVATION.

Moser and Kalton describe participant observation as a method in which the social scientist:

"...joins in the daily life of the group or organisation he is studying. He watches what happens to the members of the community and how they behave and he also engages in conversations with them to find out their reactions to, and interpretations of, the events that have occurred." (5).

Participant observation was used to study MIND for several reasons.

Firstly, it enabled a better understanding of participants' perspectives: what Bryan Wilson refers to as "empathic understanding" (6), an important aim of research by symbolic interactionists and phenomenologists (7). Wilson refers also to rational understanding, or attempts to gain objective and unbiased knowledge of a social group. It is argued that, in order to gain effective understanding from a social science perspective, the researcher must maintain a balance between empathic and rational understanding (8).
During fieldwork, I became very involved in the activities of the two Local Associations which were studied in depth. Whilst this enabled me, to some extent, to empathise with participants and to understand their perspectives, my active involvement made it more difficult for me to stand back as a detached observer, and see the Local Association more "objectively". At times during my participation, I "almost forgot" that I was there as a research student. However, it appeared easier to apply "rational understanding" and objectivity to the analysis of field notes collected from participant observation.

The advantage of this method was that it helped me to question and modify my assumptions about consumer involvement, and about which people were "consumers". This particularly happened in my participation in Zeta Club, run by Westhill MIND, which considerably changed my understanding of the nature of consumer involvement, particularly in relation to the extent that this could be "formal" or "informal". Data from preliminary interviews suggested that there was little consumer involvement, but much professional participation in Westhill MIND, compared with the Eastvale Local Association. Yet in some ways, there was more consumer involvement in Zeta Club than in Eastvale MIND's day centre, which offered considerable formal participation, and clearly defined roles and responsibilities. Participant observation enabled a depth of understanding of the nature of consumer involvement in these two Local Associations, which could not have been acquired through interviewing alone.
Participant observation yielded data which was detailed and interesting, and led to the formulation of ideas, and of questions which could be asked in interviews. A disadvantage of the method was the considerable amount of data collected, which were very hard to summarise or to quantify. It was originally intended to analyse the participant observation field notes in depth, and to use as much data from this source as from interviews. However, this proved impossible to complete because of the very considerable amount of time needed to analyse all the field notes. Instead, the study has been based largely on data from interviews. However, some usable data was generated from the participant observation; and I feel, on balance, that the use of this method has yielded information which gives a richer, more complete picture of consumer involvement in MIND.

The time that participant observation took was also a disadvantage. About five days a week, for about 12 weeks, was spent in both Eastvale and Westhill MIND. In retrospect, this period of time could probably have been reduced by at least a third, without significant loss to the information collected. Some of the data was later found to be irrelevant, but in the early stages of the study, it was difficult to decide precisely what was relevant (9). At first, it seemed best to record a great deal, rather than have very narrow ideas about what was important, without reflecting participants' perspectives. Lacey, in referring to his participant observation and other methods of research in a grammar school, describes the enormous amount of material generated (10), and a similar problem occurred in the present study.
Participant observation could have been seen as intrusive, but very few people said that they found it so. Most people accepted the research very well, and some expressed considerable interest. Two individuals made jokes about my "spying" on them, but more usual were comments suggesting that participants liked having a research student around, or that they found it easy to "forget" what my role was.

One advantage of participant observation was that it facilitated interviewing, although this was possibly more true of Headquarters and Westhill MIND, where better rapport was probably established than in Eastvale MIND.

3. SEMI-STRUCTURED INTERVIEWING.

Research methodologists have distinguished between structured, semi-structured, and unstructured interviewing. In structured interviewing, the researcher follows the order and precise wording of questions very closely, and the respondent is usually asked to choose one of a range of responses ("closed questions"). In unstructured interviewing, few questions are asked, and the respondent is given considerable scope in deciding what to say and how to say it ("open questions") (11). In the present study, most interviews were semi-structured, with a small number of closed questions with set responses, but the majority were open.
One of the main faults of the study is that it was far too ambitious. Too many people (over 200) were interviewed, and interview schedules (Appendix 1) included long lists of questions. It was originally intended to collect material on an excessively wide range of topics, and even though some of these were abandoned, the amount of data generated proved to be unmanageable. Because of constraints of time, it has been necessary to focus on a more limited range of topics. Besides those considered in this thesis, data were collected on Eastvale MIND day centre members' views on local services, and many respondents were asked about MIND's relationship with local and central government.

The following people were interviewed in the study on topics referred to in this thesis (12).
## TABLE 2.1
RESPONDENTS INTERVIEWED IN THE STUDY

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>208</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members of Council of Management/Vice Patron</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>National MIND staff members</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>National MIND volunteers</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Forum officers and members</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td><strong>National MIND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regional MIND staff</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Other regional participants</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Regional MIND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day centre members</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Non-Day centre member volunteers</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Executive Committee members</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Staff members</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Eastvale MIND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Club members</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Executive Committee members</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Non club member volunteer</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Staff members</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>Westhill MIND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumers in Local Associations with high consumer involvement</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Other participants in Local Associations with high consumer involvement</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Other Local Association participants (Preliminary field work)</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Other Local Association Participants</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respondents in other voluntary organisations</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Civil servants at the Department of Health and Social Security</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td><strong>Other respondents</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In addition, a number of other people were interviewed on topics not covered in this thesis. These respondents included about twenty mental health professionals in Eastvale and Westhill who were not involved in MIND; two MPs whose constituencies were in the Westhill area; and four members of Dutch mental health advocacy groups.

THE ASKING OF QUESTIONS

As the field work progressed, it became easier to reduce the number of questions asked. Indeed, this was necessary as it was impossible to get through about fifty questions with any but the most enthusiastic of respondents! Checklists were drawn up, listing questions in order of importance.

Fortunately, in general, participants expressed interest in the research, and out of over 200 people approached, only a small number declined to be interviewed (13). Many respondents expressed enthusiasm for the topic of research, and were articulate, and keen to share their views. Several people spent two or more hours answering questions, usually in more than one interview.

As time passed, I became less concerned to cover all the questions on the checklist, and tended to use them as starting points for the expression of ideas about consumer involvement and related topics. For most interviews, a checklist of questions, listed in order of importance, was used. If participants wanted to give long replies, or views on other topics, I usually intervened to a limited extent.
This limited structure to interviews had the advantage that respondents could talk about what was important to them, and possibly meant that there was less danger of imposing my own views. It also meant that some very detailed and interesting data were collected. After some interviews, I would feel quite excited, as respondents had such fascinating views! As the research progressed, I became increasingly interested in respondents' views and meanings, rather than my own, and this resembled a phenomenological approach (14), although there was not a conscious decision to use this.

However, there were problems with the lack of structure to interviews, which made it very difficult to order or classify the data collected. In addition, some respondents answered a relatively limited number of questions, and I obtained little material on those which were towards the end of the checklist. It was only at the stage of analysis that I became aware of the relative importance of certain questions.

In retrospect, the advice of my supervisors to keep the fieldwork within tighter boundaries was correct, but the interest and fascination of exploring different intellectual paths and ideas led me to increase the scope of the work beyond manageable limits. Although the aims of the research (outlined in Chapter 1) were formulated before fieldwork began, these aims were too wide ranging and covered too many topics. There was also a need to weigh up the benefits of enabling respondents to say what they saw as important in relation to consumer involvement, against the need to collect data which was reasonably easy to analyse, in response to a specific number of questions (15).
In the National office, and in Eastvale and Westhill MIND, the participant observation may have affected the views expressed by respondents in interviews. There was a problem related to reactivity. As a participant in MIND activities, I was sometimes informally asked my views. This meant that, before being interviewed, respondents sometimes had some knowledge of my values and beliefs. If I had not shared my views when asked, this could have been seen as distant, and not very human, but doing so may have made it more likely that respondents would give answers which they felt would please me. In addition, the fact that the research was about consumer involvement may have led some participants to appear more interested in the topic than was actually the case. It is difficult to assess the extent to which these factors influenced respondents' views, but an impression was gained that many people gave honest and reflective answers.

Another source of influence was the inclusion of some questions which were unintentionally phrased as leading towards a particular response. Examples include schedule 3, Q 11 a) "Would you like to take on more responsibility in National MIND?" and schedule 7, Q 6b. "Do you think Eastvale/Westhill MIND is sufficiently involved in campaigns for improvements in local statutory services?". In some cases, questions in interviews were constructed too hurriedly because of the large amount of other field work.

In addition, I found that I sometimes tended to express agreement automatically with things respondents said, and this may have reinforced the expression of particular views. However, a few interviews developed into
conversations or exchanges of ideas, and I had the impression that the
(possibly unwise) occasional expression of my own views did not
necessarily influence respondents' expressed views to much extent, and
prompted them to respond to questions in depth. "Conversational
interviewing" was used by Professor Zweig, who wrote:

"...I dropped the idea of a questionnaire or formal verbal
questions ..instead I had casual talks.. on an absolutely equal
footing and in friendly intercourse. These were not formal
interviews but an exchange of views.." (16).

ANALYSIS OF DATA

Classification sheets were compiled to analyse the data from interviews,
with a note made of the number of times that particular items were
mentioned, and what each individual said. This data was then quantified
into Tables.

In the thesis quotations from interviews have been chosen to illustrate
particular points. One problem with using qualitative data is that
quotations can be used to confirm a point, whilst data which refutes it
is ignored. Attempts have been made to overcome this problem by quoting
respondents' views both "for" and "against" particular positions.

The second part of this Chapter will examine the main ethical problems
which were encountered.
A number of authorities have emphasised the importance of sound ethical practice in research in the social sciences; and have argued that the researcher should, as far as possible, ensure that participants are not harmed by the research process (17). The main ethical concerns in the present study relate to:

1. The dangers of labelling or stigmatising certain MIND participants as "consumers".

2. My lack of awareness of some respondents' perspectives.

3. Openness and honesty about the research, particularly in relation to participant observation.

4. Respondents using interviews to complain about the organisation or to discuss personal problems.

5. The influence of my own values, and the difficulty, perhaps impossibility, of producing an entirely "truthful" or "accurate" account.
Firstly, there was the potential problem of stigmatising or labelling certain people as "consumers", and of making invidious distinctions between so-called "consumers" and other MIND participants. Attempts were made to avoid these problems by making it clear that I did not intend to stigmatise or label, and that questions about "consumer involvement" referred to people who had used mental health services (willingly or unwillingly), and/or who felt that they had experienced mental health problems. I tried also to be open to respondents' perspectives of who or what constituted "consumers" and "consumer involvement".

I had a number of previous roles, each of which were shared by certain MIND participants, including those of "consumer", "mental health professional" and "volunteer". Before the research, I had told few people about my role as consumer of psychotherapy. In view of the nature of the research, it was necessary to decide what to tell respondents about my past experiences. Within MIND Local Associations it seemed necessary to share my consumer experience for two reasons. Firstly, it did not set me apart as someone who was different from participants who had used services. To have mentioned only my role as a psychiatric nurse might have created a distance, and might have been dishonest. Secondly, I felt that sharing my own consumer experience would enable people to share theirs, if they wished. Sometimes this seems to have been the case. E.g a staff member commented that one participant found it easier to talk to me because she knew that I had been a consumer.
However, I did not mention this aspect of my experience to some respondents. E.g. when approaching consultant psychiatrists (who were not MIND members) and senior civil servants for interview, I emphasised my role as a psychiatric nurse, as I felt (perhaps wrongly) that this would lend more credibility to my research. On reflection, I feel it would have been more honest to have told these respondents about my consumer experience, but I am not sure that it would have been relevant.

**RESPONDENTS' PERSPECTIVES**

As far as I can tell, labelling or stigmatising people appears to have been avoided. But my lack of awareness of respondents' perspectives caused considerable ethical problems in Eastvale MIND, the first Local Association which was studied in depth. My interview schedule, with long lists of questions, failed to take sufficient account of some day centre members' perspectives and perceptions of the research. Some respondents found the schedule too long, and certain questions puzzling. At least one individual felt unable to discuss this with me, and complained to the centre manager.

I did my best to learn from this experience (18), and subsequently, I tried to be much more aware of respondents' perspectives and perceptions of the interview. In Eastvale MIND I interviewed stratified random samples of day centre members (19). However, in Westhill MIND I approached only those club members with whom I had established rapport. In addition, I was more flexible in my choice and range of questions, and tried to be more aware of signs of boredom or anxiety. All this meant
that it was more difficult to compare the responses of people with consumer experience in the two Local Associations, but it did mean that efforts were made to reduce the likelihood of causing distress or unease to respondents.

People in both Local Associations were very accepting of myself and my research, but overall, I established more rapport with, and felt closer to participants in Westhill MIND. This was for several reasons. In general, Westhill MIND participants were more enthusiastic about the research, and appeared to understand it better, and many were graduates or local students. I did not establish as good a rapport with some members of Eastvale MIND, probably because of cultural and educational differences. Eastvale MIND is in a part of England which was unfamiliar to me. Differences between the two Local Associations in selection of people to be interviewed, in ease of communication, and in respondents' enthusiasm for the research, are likely to have had some effect on the findings; but it is difficult to assess in what ways, and to what extent.

3. THE RESEARCH RELATIONSHIP

In my work as a research student (and later, as a research nurse), I have come to appreciate the value of openness and honesty in the research relationship. There are advantages in working with respondents on research projects, and in enabling them to participate in decisions about the areas to be explored, rather than the researcher imposing her/his ideas.
It was decided to study consumer involvement in MIND partly because it was known, before fieldwork commenced, that at least some participants were keen to increase such participation in the organisation (20). Participants varied in the extent that consumer involvement was salient to them, but there were many who indicated that they were committed to increasing such participation. Participants' interest in the study is indicated by the very high percentage of people who agreed to be interviewed. Many respondents had facilitated consumer involvement in MIND or other organisations, and interview responses indicated that some had thought deeply about the issue. Listening to respondents' views helped me to increase my understanding of consumer involvement, for which I am very grateful.

Bulmer has distinguished between overt and covert research, particularly in relation to participant observation. He argues that covert research, performed without respondents' knowledge or consent is unethical (21), a view with which, in general, I agree. From the start, efforts were made to clearly inform participants about the research and find out what methods and areas of exploration were acceptable to them. People were given opportunities to express ideas and ask questions. The research was discussed both informally and in a few meetings, but I should have been more aware that not all Eastvale MIND day centre members were keen to be interviewed in depth.
4. PARTICIPANTS' USE OF INTERVIEWS

One ethical problem concerned ways in which participants used the research relationship. A few respondents used interviews to talk about personal problems in detail. When this occurred, it was tempting to adopt a "counselling" role, but to do so would not have been in the interests of people who needed long-term support, in view of my limited time with each Local Association, and the clash with my role as a research student. In such circumstances, I generally explored with the individual where (s)he could get on-going help and support.

A relatively small number of people, in informal conversation or interviews, told me things about their Local Associations which other participants might not have wanted me to know. Two respondents made several complaints about their Local Association. This use of myself as a confidante involved two moral dilemmas. Firstly I was listening to, and perhaps encouraging, what could be seen as "gossip" on matters which, I felt, I was not entitled to hear. Secondly, some of this material might be of relevance to the study, and if so, should it be used? I decided that, whilst such material might add to the accuracy of my account, this had to be overridden by a responsibility to respect confidentiality and to consider participants' feelings.

5. VALUES AND "TRUTH"

Finally, my own values are likely, perhaps inevitably, to affect the "accuracy" and "truth" of this study (22). My own interest in, and
commitment to consumer involvement in mental health services, led me to choose this as a topic for research. As the fieldwork progressed, I became more aware of my own values and assumptions, and their possible influence on the study. In particular, I became aware of my belief that consumer involvement was necessarily a "good thing", and that its extent in an organisation could be fairly precisely estimated: e.g. on four-point rating scales. The more I studied consumer involvement, the more complex it appeared, and I became increasingly interested in respondents' perspectives. I came to realise that it was not enough to assume that consumer involvement is a "good thing". Instead, it was necessary to ask questions such as: "Who should be considered a consumer?" "What level, degree and type of consumer involvement is optimum for a particular individual, and for the organisation as a whole?" "What are the problems and benefits of consumer involvement?" "What factors facilitate or hinder such participation?".

The rest of this thesis attempts to answer these questions. The next chapter explores the meaning of participation and related concepts.
CHAPTER 3

THE MEANING AND DEVELOPMENT OF CONSUMER PARTICIPATION

The concept of participation is central to much political theory, and is particularly emphasised in the literature on participatory and representative democracy (1). The perceived shortcomings of the latter are often stressed by using the language of participation (2). Consumer involvement in MIND can be better understood by considering participation within the wider context of social policy and the voluntary movement for mental health. For this reason, the next two chapters include an examination of the meaning of "consumer", "participation", and related concepts; the recent development of participation in social policy in this country; and the characteristics, types and dimensions of participation. Chapter 5 considers the development of participation in the voluntary movement for mental health.

THE CONCEPT OF "CONSUMER"

In Economics the term "consumer" refers to an individual who purchases goods or services. Consumers in free markets in capitalist societies choose amongst a variety of items which are offered for sale. The amount of choice of each individual depends on her/his purchasing power (3).
From the nineteen sixties the term "consumer" has been used, to an increasing extent, in both the UK and the USA, to describe a user of those statutory or voluntary services which are free at the point of consumption. Until the development of the Welfare State, the only "consumers", in the economic sense, of health or welfare services were the rich, and working people with regular, reasonably paid employment who joined organisations concerned with mutual aid such as friendly societies. These organisations paid their members on retirement, and in times of sickness and unemployment. People who were poor received free health and welfare services from wealthy benefactors or voluntary organisations, or from the state. (4) State services such as workhouses were seen as, and indeed were often meant to be, stigmatising. The aim of relief was often to inculcate self help and to deter people from seeking assistance (5). Words like "suppliant", "recipient", "beneficiary", which imply a passive, inferior position to the donor are intentional and accurate descriptions of the status of many users of charitable and state services until the early twentieth century. By comparison, therefore, the term "consumer" implies a certain amount of choice, and of equality, or even superiority, in relation to the giver of the service.

From the time of the election of the Liberal Government in 1905 until after World War 2, reforms were made to provide certain benefits and services as a right; and whilst Poor Law services persisted, there was increased awareness by Governments of the stigmatising effects of the Poor Law, with consequential efforts to develop a variety of services outside its remit (6). The passing of the National Health Act and National Assistance Act in 1948, made available a wide range of health and welfare services, as of right, to those who needed them.
Nevertheless, certain benefits and services are still seen as stigmatising, even when they are universal, rather than means-tested (7). The views of many members of the public in this respect do not accord with those of many politicians and professionals. The increasing use of the term "consumer" to refer to a user of health or welfare services appears to have coincided with:

a) new ideas in social policy, social work and the health service concerning the role and status of the recipient of services and the professional - client relationship;

b) the development of a so-called "consumer society" from the mid nineteen fifties onwards.

The late nineteen fifties and sixties was a time of rising economic prosperity in the UK, with many people having an increasing amount of money to spend on a considerably widening range of goods. There was increased concern to protect the interests of consumers, with the setting up of a voluntary organisation, the Consumers Association, in 1956, and the passing from 1959, of a variety of Acts to protect consumers (8). A large number of consumer groups was formed, including organisations of users of statutory services, such as the Patients' Association and the Advisory Centre for Education (9). The idea of consumer protection, but not consumer choice, gradually spread to social and other public services (10). According to the Report of the Committee on Local Authority and Allied Personal Social Services (the Seebohm Report):
"...the consumer of the personal social services has limited choice among services and thus needs special opportunities for participation. The justification of consumer consultative machinery in nationalised industries contained in the recent Consumer Council study also applies to the personal social services." (11).

From the seventies there was increased concern to consider the needs of consumers of public and social services and of paid professional services, areas with which the Consumers' Association became increasingly concerned. Lord Young, a leading figure in the consumer movement and founder of the Consumers' Association, emphasised the needs of consumers of social services (12). The National Consumer Council, founded in 1975, was set up to protect the interests of a variety of consumers, including users of public, health and social services (13). In 1986 the National Consumer Council produced a report of "clients' redress in social services departments" (14).

Godyer commented on two perspectives of "consumer representation in the public and social services":

..The first is the individual perspective.. are the institutions operating for the benefit of their users, rather than the users being inconvenienced for the benefit of the institutions? The second... perspective..[is] do the people who pay for and use the services make any noise about their view of how best to spend the money?...(15).
Whilst most recipients of pre-twentieth century welfare services may have been poor, people with physical or mental illness or handicap have always come from a variety of social classes. The relationship between doctor and patient was affected by the latter's social class and wealth (16). The wealthy paid for medical attention and were thus "consumers", in the economic sense, of this service. Studies of the doctor-patient relationship have drawn different conclusions about the relative amounts of power of the two parties, some emphasising the doctor's prestige and expert knowledge, others pointing to ways in which the patient can exert influence or negotiate with the doctor (17). The perceived mental health of the patient is one factor which appears to affect the extent to which (s)he is allowed consumer status. In the eighteenth and nineteenth centuries both medical and lay staff exercised considerable coercion, and ignored the wishes of upper class and middle class people with mental illness, despite the latter's social status and ability to pay. This applied even to George III whose "mad doctors" gave him treatment against his will, and refused to grant many of his requests. In many cases, the mentally ill patient's relatives were viewed as the consumers of professional services, and it was their wishes, rather than those of patients, which were acceded to by the doctor or other professional (18).

Despite the developing power of psychiatrists, Klein points out that, until 1911, when National Insurance was introduced, "few doctors had high social prestige and income" (19). General Practitioners were:
"...in the position of small tradesmen who had to do as instructed by the **customer**, especially doctors engaged in "contract medicine", through which doctors were hired by Friendly Societies to look after their members.

"In the working class.. the **customer** was always right, and usually insisted on cheap medicine.." (20).

From the days of the Friendly Societies, patients have had some choice in deciding their General Practitioners. During negotiations concerned with the National Insurance Act, 1911, "the British Medical Association emphasised the importance of "free choice of Doctor by patient" (21). Under the National Insurance Act, patients could chose any General Practitioner from a "panel appointed by the local Insurance Committee" (22). Choice of hospital treatment depended on ability to pay, and was usually limited for poorer people using the voluntary hospital system before World War 2, or for National Health Service patients (23).

Writing in 1971, Logan et al commented:

"..To talk about someone as a consumer normally implies he has freedom of choice - and has the information required to exercise that choice rationally. The consumer of medical services is very rarely in such a position. The more he needs medical services (i.e., the more acutely ill he is), the less choice he has.." (24).
Several writers comment that many psychiatric patients have little choice of services, and often little say in matters concerning their everyday lives or treatment (25). Psychiatric patients have been described as powerless, and in an inferior position in their relationship with mental health professionals, a point which will be considered later in this thesis (26). Recipients of private medicine have often been referred to as "consumers" since the nineteen fifties, particularly in American literature. During the seventies, National Health service patients, including those using psychiatric services, were referred to as "consumers" in a number of papers, particularly those on consumer satisfaction (27). This decade saw an increased interest in consumer views, which was reflected in the setting up, in 1969, of the Hospital (later Health) Advisory Service, to assess Health Services for older people and patients with learning disabilities and mental health problems, following a series of scandals in long stay hospitals (28). The post of Health Services Commissioner was created in 1972 (29). Several studies of consumer views of Health Services were conducted (30), including a survey, by the Royal Commission on the National Health Service of patients' attitudes to their treatment (31).

King argues that, with reorganisation in 1974, the National Health Service changed from being "...a totally enclosed and secret institution." (32) to offer opportunities for increased public involvement, with the creation of Community Health Councils which represented consumer interests, and increased interest in consumer views (33). Other authorities have argued that the reorganisation of the National Health Service decreased or inhibited such participation (34). Draper et al point out that Central Government exerted control over membership of
Health Authorities, and that "...the consumer's voice [was]... heard only in Community Health Councils which had no executive powers." The reorganisation has been criticised for failing to facilitate participation because of its top-down decision making, and for its"...shift away from participative decision processes, and towards mechanistic and technocratic processes." (35). "By the late seventies, consideration was given to a simplified health service administration, which might be more sensitive to community needs and responsive to the consumers' point of view." (36), with attempts made to make the NHS less bureaucratic in further reorganisation in 1981 (37).

Under Conservative Governments since 1979, there has been increased emphasis on "consumerism" in the National Health Service. According to Richardson and Bray, consumerism "...refers to the need to acknowledge the interests of consumers in health delivery as well as the pressures they are likely to bear on the system." (38). Attempts have been made "to make the National Health Service more patient oriented (39). Since the early seventies, several DHSS/DOH publications have referred to the importance of considering the needs and views of consumers (40). The rise in consumerism in the National Health Service appears to have come at a time of increased emphasis on self help and on people's responsibility for their own health, and a recognition by political parties that many people wanted more participation in services (41).

An endorsement of consumerism in the National Health Service came from the National Health Service Management Enquiry Report (the Griffiths Report) (42), published in 1983, which laid emphasis on "assessing the quality of health care" (43), particularly from the viewpoint of the
patient, who is often referred to in the Report as the "consumer" or "customer" (44). Close parallels were drawn between the health service and the commercial market, and it was recommended that Health Authorities should conduct "market research type surveys of NHS consumers' wishes and opinions" (45).

"..Businessmen have a keen sense of how well they are looking after their customers. Whether the NHS is meeting the needs of the patient, and the community, and can prove that it is doing so, is open to question.." (46).

The Report further recommended:

"The Management Board and Chairmen should ensure that it is central to the approach of management, in planning and delivering services for the population as a whole, to

"1. ascertain how well the service is being delivered at local level by obtaining the experience and perceptions of patients and the community...

"2. respond directly to this information;

"3. act on it in formulating policy;

"4. monitor performance against it.." (47).
The Griffiths Report commented on health service management's lack of commitment to "consumer related tasks" (48), and recommended that general managers should be appointed to improve customer relations, and to increase responsiveness to public and consumer expectations. Griffiths also recommended that ministers should review the National Health Service to ensure that this objective was being met (49). The Griffiths Report appears to have influenced an increase in attempts to assess consumers' satisfaction with health services and to be more responsive to their needs. A survey in 1985 by the National Association of Health Authorities found at least 80 schemes for improving responsiveness to consumer needs (50). Since the mid eighties, many measures of quality, often taking the consumer's perspective into account, have been devised, as components of quality assurance and total quality management (51). Such measures have included patient satisfaction studies of mental health and other services (52). The Patient's Charter, produced in 1991, stresses the rights of patients, the standards of service which they can expect, and the value attached to patients' views (53). In addition, the monitoring of services and the meeting of consumer needs, have been stressed in the white paper "Working for Patients" (54) and the NHS and Community Care Act, 1990 (55).

**CONSUMERISM IN THE PERSONAL SOCIAL SERVICES**

From the nineteen sixties, there has also been increasing concern to apply the principles of consumerism to personal social services. In the USA during the Kennedy and Johnson administrations, legislation was passed to make a variety of social services more accessible and more aware of
consumers' views and felt needs (56). Market research techniques and other surveys of consumer opinion were used to discover what consumers thought of services (57). Writing in 1975, Perlman commented:

"...the consumer's perspective has emerged in the past ten years in all aspects of life in the United States with greater force and clarity than ever before. In social welfare, consumers' interests are being articulated and their interests mobilised." (58).

In the United Kingdom, the Seebohm Report stressed the importance of considering the consumer view (59). The report provided the impetus for studies of consumer satisfaction with social work, with several studies being done in this area (60). A growth in interest in the consumer view was reflected in an increased recognition of the imbalance of power in the relationship between client and social worker, and of discrepancies between their views (61). Later DHSS reports of relevance to social work also stressed the importance of the consumer viewpoint. Examples include the Barclay Report which included a survey of consumer views of social work (62), and "Care and Treatment in a Planned Environment", which emphasised the importance of professionals considering the views of children and young people in community schools (63). In the seventies and eighties a number of DHSS documents on services for people with learning disabilities and mental illness stressed the importance of views and needs of consumers and their relatives (64). Eg. "Care in the Community" states in relation to community care:
"..Most people who need long-term care can and should be looked after in the community. This is what most of them want for themselves.." (65).

The House of Commons Social Services Committee Report on Community Care (the Short Report) recommended that the views of people with mental illness and learning disabilities and their relatives be considered, especially when long-term facilities were being closed. In its response to this report, Central Government recommended that "NHS managers be reminded that development of services should be informed by consultation and consumer rights." (66). In 1987 Sir Roy Griffiths was appointed to chair a committee further investigating community care of elderly people and people with mental illness and learning disabilities. Part of the committee's remit was to assess this from the consumer perspective (67). In addition, consumer participation, and the rights of users of social services, and their informal carers, have been stressed in the Wagner Report on residential care, the white paper "Caring for People", the Children Act, 1989, certain sections of the N.H.S. and Community Care Act, 1990, and several reports of the Social Services Inspectorate (68).

**TERMS TO DESCRIBE SERVICE USERS**

The use of particular terms to describe recipients of Health and Social services reflects their status in relation to the providers of services. Terms such as "beneficiary" and "supplicant" denoted the recipient's passive and inferior role (69) whilst the term "patient" in health care is said to suggest passivity and acceptance of suffering (70). Shaw comments on the wide variety of terms used to describe recipients of social work services.

"..From one point of view it does not not matter what name is given to the users of the personal social services. Yet there is a strong normative element in the recent plethora of new
designations, stimulated by a desire to emphasise individual rights, and a claim that the user of welfare services is in all important respects like other people." (71).

Certain words have been deliberately coined by professionals to reflect changes which they were trying to effect in their relationships with service users. Thus, from the late nineteen forties, the word "resident" was used to describe members of Therapeutic Communities who were receiving treatment. "Resident" was felt to reflect more accurately the individual's involvement in decision making and responsibility in a democratic, permissive environment (72). The word "claimant" in social services signified a right to welfare. "...A claimant carries more power than an applicant.. [and] often implies a statement about the value and importance of corporate action." (73). The term "client" reflected the wish of social workers to give recipients the rights and status of users of professional services (74). However, unlike the clients of most professionals, some people who receive services from psychiatrists, psychiatric nurses and social workers, do so reluctantly, or against their will; and in some cases, the professional may be serving the interests of other people besides the client (75).

Some authorities have indicated the advantages of viewing recipients of health and social services as "consumers", with its implications of choice, equality with service providers, and of lack of stigma (76). Morris comments that if social services view social work clients as "consumers", they are likely to respond better to client demand (77). According to Jef Smith, "a particular merit [of the term consumer] is that it focuses attention on demand, in a field in which the supply side has traditionally dominated the debate." (78). Lazare et al refer to the
different expectations that therapists and patients have of psychiatric treatment, and describe the advantages of a "customer approach to patienthood", in which treatment is negotiated by the patient (79). The involvement of British Central Government in a "consumer approach" within the National Health service has already been outlined (80).

A number of authors comment that the application of a term in Economics is of limited use in Health or Social Services. Fisher et al state that, whilst a customer in a market exercises choice and influences competition and production of goods, this is of limited significance to the consumer of welfare services who has little autonomy (81). Other critics have pointed out that, unlike consumers in the open market, many users of health and welfare services do not pay for them (82), and exercise little or no choice or power in their selection of services (83). The complexity of some professional services makes it harder for consumers to make decisions about them than is the case with many commercial goods (84). The usefulness of the concept of "consumer" in Health Services has been questioned by van den Heuvel, who stresses the need for greater conceptual clarification in its use. He points out that within health policy, "consumer" can refer either to "control of cost prices, outcome and efficiency", or to "self control and participation" (85). There are also problems with using "consumer" to describe people who receive health or social services against their will, or because they have no choice: eg, patients compulsorily admitted to psychiatric hospitals, people subject to probation orders, and children taken into care and their parents. There is a social control element in some health and social services provision (86), and in some cases the "consumer" is someone who requests, or pays for a service which is given to a reluctant or
unwilling recipient. Examples include patients detained by order of judges in psychiatric hospitals under a section of the Mental Health Act, 1983 (87), and reluctant psychiatric patients whose relatives pay for their treatment in private hospitals (88). Klein and Lewis graphically describe the difference between the consumer's relation with the professional and the shopkeeper: "What distinguishes a professional from a shopkeeper is that his duty lies in doing for the client what professional knowledge and professional ethics dictate, not what the client wants..." (89).

Although the term "consumer" has sometimes been used to replace other words which are thought to be stigmatising, some authors comment that "consumer" is itself stigmatising, or diminishes the status of the user of services. Thus, Mangen and Griffith argue that "the promotion of the role of consumer depresses the status of a [psychiatric] patient by introducing a misleading supply and demand interpretation " (90). Warren states that, in relation to American mental health services, the term "consumer" diminishes the status and viewpoint of service users (91). Bellin comments that it is stigmatising to differentiate between "consumers" and "non consumers" (92), a view which was expressed by some MIND participants in the present study (93).

Finally, there is the question: "Who is the consumer of health and social services?" This question is important in relation to who should participate in services, and will be considered in more detail during the ensuing analysis of participation. The term "consumer" has been used to describe, not only direct users of services, but their relatives, local citizens and rate payers (94). The rest of this chapter is concerned with the meaning, types and dimensions of participation.
WHAT IS PARTICIPATION?

Several authors note the wide range of meanings attributed to participation (95), and the lack of agreement about the meaning of the word (96). Boaden et al state that "participation is a chimeric word, capable of meaning many things to many people" (97), whilst Fowler comments that a lack of shared meaning of participation leads to "confusion, conflict, frustration" (98). According to Pateman, "participation" is used to refer to "a wide variety of different situations by different people" (99).

The Penguin English Dictionary defines participation as the "act of taking part or sharing.." (100). Richardson and Boaden et al cite other dictionary definitions:

"..a taking part (with others) in some action or matter.." (101).

"..The Shorter Oxford English Dictionary gives at least two definitions: one implies the idea of forming part of something, the second that of sharing something in common with others, or taking part with others, in some action or other.." (102)

Richardson and Boaden et al state that these dictionary definitions raise further questions about the meaning of "taking part", the precise nature of participation, and who participates (103).
Many definitions of Participation are given in the context of involvement within a particular sphere of activity: e.g., in politics, social policy, management, industry (104). General definitions of participation in the literature seem to be less common. Richardson suggests that a superficial definition of "to participate" might be "to take part, to become involved", but argues that this definition ignores the complexity of the concept (105). Verba et al define participation as "acts by those not formally empowered to make decisions - the acts being intended to influence those who have such decisional power, and successful participation refers to those acts that have (at least in part) the intended effects" (106). Consumer Participation, community participation and citizen participation have been described (107), the last two terms being particularly prevalent in the American literature. There appear to be no definitions of consumer participation in the literature reviewed (as opposed to definitions of "consumer" and "participation"). The following definition of consumer participation, based on ways in which the term is used in the literature, is proposed:

The involvement of users of services in responsibility and/or decision making which has an intended impact on services and/or policies which affect the individual participant and/or other service users.

The characteristics and nature of such participation are examined below. The term consumer involvement appears to be a synonym for consumer participation, and was used in this way by most MIND participants during the period of fieldwork. A literature search has not revealed any consideration of differences in meaning between the two terms, and
descriptions of "consumer involvement" by respondents in both this study (108), and that of Fowler (109), suggest that members of voluntary organisations for mental health saw "consumer involvement" in the same way that others view consumer participation.

According to Caro, "community participation... can be broadly defined to include the involvement of all who have an interest in a community." (110). Community participation usually describes the involvement of people who live in a relatively small geographical area: eg, a rural community, town or suburb. In relation to third world development, the United Nations suggested that community participation occurred "..in small communities composed of individuals "at the lowest level of aggregation at which people organise for common efforts"" (111). The usage of "Community Participation" and "Citizen Participation" seems to overlap. Citizen Participation has been defined as a "..belief that government should be a means by which the governed can express their wishes and choose their programmes" (112), whilst Arnstein declares that it "..is a categorical term for citizen power. It is the redistribution of power that enables the have not citizens, presently excluded from the political and economic processes, to be deliberately included in the future." (113).

The terms "relative participation" or "relative involvement" refers to the participation of people with a family member who has a particular problem, and/or uses a particular service. Examples include the parents of children who attend school, or who have a disability, and the relatives of people with mental illness (114).
Participation has been advocated, described and defined in relation to many areas, including involvement in Central Government and Local Government, in policy making and policy implementation in various areas of social policy, in industry, and within institutions run by health, social services and penal organisations (115). Participation has also been described in mutual aid or self help groups and other types of voluntary organisation (116). Yet several writers comment on inadequate definitions or poor conceptualisation of participation in the literature. Definitions have been described as vague (117), confusing (118), and ambiguous (119). Inadequate conceptualisation has been described (120). Fowler states that it is difficult to define participation because of the lack of literature about the concept. He attributes the latter to a reliance on authority and professional expertise and because "the founders of the welfare state had no particular reason to consider [participation].." (121). A number of critics refer to the diversity of views on the meaning of participation (122). Both Fowler's study of mental health consumer groups and the present study found that participants attributed a wide variety of meanings to the term "consumer involvement" (123).

"..the central difficulty in discussing [citizen participation] is that almost everyone has a different view based on unspoken assumptions and perspectives, that in turn spring from differing personal imperatives, political, philosophical, social understanding and other variables. (124)."
"...the problem with participation is that it is so ambiguous: each is free, like Humpty Dumpty, to make the word mean exactly what he or she wishes it to mean." (125).

Several authorities describe lack of adequate assessment of the value or effectiveness of participation and the problems of evaluating this (126). The difficulty of implementing policies for participation and the reasons for this have been described. The latter have included poor conceptualisation and a lack of understanding of the nature of participation (127), ambiguity in recommendations for policy implementation (128), lack of agreement about goals, types and meanings of participation (129), the attitudes of staff in organisations with which participants are involved (130), and a lack of skills and commitment in participants (131). Difficulties in implementing participation on poverty programmes in the USA, because of these and other problems, have been extensively described (132). In particular, there has been analysis of the lack of awareness of the implications of a clause in the (USA) Economic Opportunities Act, 1964, which urged the "maximum feasible participation" of poor people in poverty programmes, and uncertainty about the precise way in which participation should be implemented (133). In the United Kingdom the Skeffington Report has been "critised because it failed to make a clear distinction between participation specifically in decision making and public relations" (134). Cook emphasises the importance of clarifying "what we mean by consumer participation if we wish to pursue it as a policy" (135).
Several authors note that "participation" is sometimes used as a "value word", and seen by many of its proponents as being a "good thing". Gibson comments on social scientists' tendency to confuse questions of value with those of "fact" and to fail to make their own values clear (136). Several authorities refer to the enthusiastic and uncritical acceptance of participation by some of its proponents. Thus, Handy writes of participation in industry that it is "...one of those 'good' words with which it is hard to disagree..." (137). Rose comments "...participation is synonymous with virtue..." (138). McEwen et al refer to the "emotive connotations" of consumer participation in health care (139), and other writers comment that participation is seen as being good or desirable for people (140). Participation is sometimes seen as a panacea for social ills. Rose views an increase in participation by the public "as a response to economic and social crisis" (141).

Several authorities criticise this uncritical enthusiasm for participation (142). Hill comments that "'participation' and 'involvement' may become catch-phrases, rather than real solutions. "These words have become fashionable" (143). Other writers comment on insufficient analysis of the concept (144) and lack of objectivity (145). Hutton comments that in public enquiries concerned with planning, the ideology of participation conflicts with the ideologies of protecting private property and efficient administration (146).

Problems in defining, conceptualising and implementing policies for participation appear, in part, to be related to the complexity of the phenomenon. Brager et al comment that "the idea is a conglomeration of ideas and values" (147), and many writers describe a diversity of different types of participation in a wide variety of contexts (148).
PARTICIPATION IN THE WELFARE STATE

In this country enthusiasm for participation in social policy appears to be of recent origin. There was little expressed interest in participation in the early days of the Welfare State, with few references to public participation in Central Government documents of the late forties and fifties. There is a number of references to the continued importance of the voluntary sector in the Acts of Parliament which led to the establishment of the Welfare State (149), but "the founding fathers of the current Welfare State, both in Britain and elsewhere, never felt called upon to address [participation] at all." (150). In the early days of the Welfare State, decisions were made by political, professional and managerial experts, with little thought being given to public participation (151).

In the USA, there was considerable political interest in participation during the Kennedy administration in the early nineteen sixties. Federal and State Governments were seen by many as remote and unresponsive to the needs of many people, particularly those who were poor and black. A wide variety of programmes was evolved to enable disadvantaged people, especially those in poor urban areas, to participate in efforts to improve their housing, education and other services. Attempts were made to make services more accessible to disadvantaged people (152). Public participation, and to a lesser extent, the participation of clients, was encouraged in Community Mental Health Centres, which were set up in the early sixties, in part to replace state-run custodial psychiatric institutions (153).
There were increased demands for public participation in Britain in the late sixties and early seventies (154), partly influenced by developments in the USA (155). Labour Administrations set up Community Development projects to increase participation of local people in deprived urban areas. At this time there was considerable development in professional community work, which aimed to enable people to bring about changes in their localities, sometimes through political action (156). Many of the Government-funded Community Development and other projects ceased after withdrawal of funding in the early seventies (157).

The participation of parents in the education of their children, eg. through parent-teacher associations, and of tenants in policies concerning their housing was encouraged by a variety of Central Government reports in the sixties (158). This decade saw a number of protests about the construction of major roads and redevelopment of towns, and the Skeffington and Maud reports advocated participation in Public Planning, and some of their recommendations became enshrined in legislation (159). The report of the Committee on Local Authority and Personal Social Services (the Seebohm Report) recommended the participation of local citizens in Personal Social Services:

"...We see a high level of citizen participation as vital to the successful development of services which are sensitive to the local needs..." (160).
"...Implicit in the idea of a community-oriented family service is a belief in the importance of the maximum participation of individuals and groups in the community in the planning, organisation and provision of the social services..." (161).

The call for "maximum participation" in the Seebohm Report is reminiscent of the "maximum feasible participation" clause in the USA 1964 Economic Opportunity Act (162). The Seebohm Committee's enthusiasm for participation was not reflected in subsequent legislation for the personal social services, which did not mandate mechanisms for achieving participation, other than the establishment of social services committees (163). Outside individual client-professional relationships, participation in social services does not appear to have become widespread in this country, although accounts have been given of the participation of voluntary organisation representatives on committees for various client groups (164), and in residential and other social services (165).

After the passing of the National Health Service Act, 1948, public participation in the running of hospitals continued under Hospital Management Committees, which included many laypeople. These committees were abolished under the 1973 NHS Reorganisation Act. Opportunities for lay participation continued in the newly established District and Area Health Authorities, but many of the members of these authorities were selected by the Minister. The 1973 Act provided for the setting up of Community Health Councils, which were to act as "public watchdogs" and to advocate on behalf of patients and the public (166). Membership of
Community Councils, at least in their early days, tended to be dominated by white middle class men (167).

Despite an emerging interest in patients' views, and the establishment of the Hospital (later Health) Advisory Service, and the post of Health Service Commissioner (168), reorganisation was criticised by some authorities for making the National Health Service more remote from the consumer (169). From the seventies there was gradually increasing awareness of the importance of the consumer viewpoint, (170), with a number of Government reports emphasising the importance of considering the needs and views of patients and their families (171).

In both the UK and the USA some Government documents have advocated, and in a few instances, mandated, specific types of participation. The Economic Opportunity Act, 1964, has been criticised for not clearly delineating what was meant by "maximum feasible participation" of poor people (172), although Robert Kennedy declared that this referred to "the involvement of the poor in planning and implementing programs: giving them a real voice in their institutions" (173). A Government Department, the Office of Economic Opportunity, offered guidance about ways of ensuring the participation of poor people, and eventually regulated that one third of the members of Local Boards which administered poverty programmes should, themselves, by poor (174). A 1967 policy statement on citizen participation in a Model Cities Programme stated that participation involved "planning and carrying out the programme" and of "introducing the views of area residents in policy making" (175). Later legislation made mandatory various types of participation in Community Mental Health Centres, with specifications about the involvement of citizens in running these centres, and the assessment of consumers' views (176).
Some British Central Government documents have also specified particular types of participation. An early example was the 1944 Education Act, which stated that intended school closures must be publicly announced to consider objections by parents (177). The Town and Country Planning Act, 1968, specified that planning authorities were to publicise plans, and to inform people of their right to make representations and to give them opportunities to do so (178). The Seebohm Report distinguished between citizen participation in "providing services or helping...participation in the process of decision, particularly in planning...[and] participation in the forming of groups aiming to publicise particular needs or shortcomings in provision.." (179). The report also refers to the participation of consumers on Social Services committees and sub-committees (180). More recently, D.H.S.S./DOH documents have recommended the consultation, and direct participation in planning services, of consumers and their relatives, and the provision of fora for them to express their views. Examples include a 1980 White Paper which recommended consultation and direct involvement in service planning of the parents of people with learning disabilities (181); and the Short Report which recommended that both consumers and their relatives participate in the planning and provision of mental health and learning disability services (182). Two D.H.S.S. discussion papers stress the role in planning of consumers of primary health care, including community nursing. The value of consumer views, and of fora to express these, is stressed. "Individual members of the public, as recipients of services, are often better placed to judge the quality of services than the N.H.S. bodies responsible for them". (183).
REASONS FOR AN INCREASED INTEREST IN PARTICIPATION.

A variety of reasons for an increased interest in participation has been put forward. A number of authorities comment on the influence of wider societal changes in values and beliefs. These include decreased acceptance of authoritarian leadership (184), and increased scepticism of professionals and other "experts" (185). Some movements for participation appear to have been inspired by developments in radical thought. Holland states that federal Government policies for participation in poverty programmes in the USA "...reflected cultural developments which stressed individual autonomy.", and comments on the influence of civil rights and student movements and the "awakening political consciousness of minority and disadvantaged groups" (186). Factors said to have influenced a growth of British Central Government interest in participation at this time include the development of the "permissive society" and of a participatory culture amongst students (187), and an increase in local consumer groups (188). Consumers became better organised, and an increased number of people used local services. There was a rise in expectations of services. (189). Participation is said to have flourished partly because of fashionability, and because participation in one area led to demands for participation in others (190).

Participation is said also to have increased because it fulfilled needs of professionals and administrators. Facilitating participation was seen as an important part of good practice (191). Increasing importance was attached to the self-determination and autonomy of the social work consumer, who was seen as a client with rights within an equal relationship with the social worker, rather than as a passive recipient (192). Such ideas were reflected in the Seebohm Report (193).
The early seventies saw considerable developments in community work, with some members of this profession encouraging people to actively participate, often politically, in order to bring about changes (194). At this time there was increased interest in clients' perspectives (195). From the fifties, there were considerable developments in theoretical considerations of power in the doctor-patient relationship, with some authorities advocating more equality between doctor and patient (196). This resulted in some changes in practice, particularly in psychiatry, where the Therapeutic Community movement, which originated in World War 2, became fairly widespread in the sixties. The result was a liberalising of hospital regimes, fewer barriers between patients and staff, and greater participation of patients in their own and others' treatment and in the running of wards (197). From the early seventies both general practitioners and patients in a few areas set up "patient participation groups", which aimed to increase consumer participation in certain aspects of General Practice and health education (198). The move for consumer participation in health care was further facilitated by the setting up of the Patients' Association (1965), which represented patients' views, the College of Health (1983), and Health Concern (1985), set up to protect National Health Service resources (199).

Participation is also thought to have increased because of a growth in size and complexity of various Government departments, Local Government administrative units, and of particular services (200). This resulted in decision makers becoming more remote from consumers, and has led to a "demand...for developing participatory mechanisms"(201). One purported reason for Community Health Councils was to enable the public to have a voice in a larger and more bureaucratic National Health Service (202).
The encouragement of participation has been ascribed both to a wish by policy makers to produce more effective services and policies (203), and because of the perception of its value to consumers, eg. as a basic right, a means to protect their rights or interests, grow in skills (204) and gain psychologically in terms of increased fulfilment, self-esteem, responsibility and understanding (205). Participation has been described as indicating "the dignity and worth of the individual" (206), and as a valuable resource, since it enables the representation of the consumer perspective (207).

Participation has been said both to increase (208) and decrease in times of scarce resources (209). Some authorities suggest that recent increases in participation have occurred because of its value to politicians, professionals and other people in positions of power (210). Providing opportunities for participation has been seen as an agent of social control. Thus, according to Holland, the provision for participation in the Economic Opportunity Act, 1964, has been seen by some "as an effort to channel the civil rights movement into a socially acceptable mould" (211). Some critics have described participation as a means to legitimise or support authority, to enable the co-option or incorporation of critics, or to diminish the impact of pressure groups (212).

The unquestioning enthusiasm of some proponents of participation has been described earlier in this chapter. Participation has received approbation from politicians of a variety of political parties and for a diversity of reasons. For some politicians on the left, increasing participation in policy making is a value in itself (213), or because it
"symbolises attempts to find formulas for social justice, democritisation, and liberty... and because it exhibits... empathy with the disadvantaged.." (214). Politicians on the right have emphasised gains from participation of increases in efficiency, self-determination, and responsibility, and decreases in the size of government (215). The founding of the Social Democratic Party in Britain "was partly fuelled by concern over ..the need to foster greater participation." (216).

Richardson concludes that in the early eighties enthusiasm for participation had diminished, and attributes this to a change in fashion, more pressing problems such as inflation and unemployment and the fact that participation had already been implemented in some areas (217). Smith refers to a decline in Central Government popularity of participation from the mid seventies (218). In contrast, Boaden et al conclude that "..the economic, social and political climate of the late nineteen seventies and early nineteen eighties has been more encouraging in terms of motivating participation than is perhaps true of the late nineteen sixties and early nineteen seventies." (219).

Some authorities have described limitations in opportunities to participate. This is said to vary with different client groups and issues (220) and in different services (221). The considerable range of consumers' views is also said to make adequate representation difficult (222). Despite attempts by community workers to facilitate participation in working class areas (223), much participation is said to be largely restricted to certain localities, and to people who are middle class, well organised and articulate. Such people have been said to be
unrepresentative of the consumers that they represent (224). Imbalance of power between consumers and other participants is also said to inhibit consumer participation, and is considered below (225). Practical constraints to participation have been described, including committee structure (226) and jargon, limitations of time and space (227), the determination of certain policies at central, rather than local levels (228); and in the National Health Service, the nomination, rather than election, of many health authority members (229). Boaden et al comment that there is "no service where participation is very high...elite domination of public service is universal" (230). They conclude that "participation has not usually achieved all its proponents wished.." (231).

Some authors point out that many people do not want to participate because of other commitments or the costs involved (232). Brager et al note, that in the USA "...organisers frequently try to induce participation in people reluctant to participate" (233), whilst Leo Smith concludes that it is "unrealistic to expect widespread participation" (234).
A number of items have been delineated as qualities or characteristics of participation. Activity has been considered an important component. Thus, Richardson describes participation as "sharing in an activity, undertaking activities with others" (235), whilst McEwen et al state that, in health care, participation entails active involvement, rather than passive co-operation (236). One study of self help groups includes, among dimensions of participation, a subjective feeling of being involved, physical attendance at meetings, and involvement in particular activities such as campaigning, and giving help to other members (237). McEwen et al state that participation in health care is characterised by self help, democratisation and deprofessionalisation (i.e. reduction of the power of the health care professional) (238). Other characteristics of participation which have been described include self help, or mutual aid (239); the protection or expression of rights and choices (240); involvement in, or control of, the making or implementation of decisions or policies (241); and accessibility, eg. to people in positions of power (242). Participation is also said by many authorities to involve shifts in distribution of power, in favour of consumers or citizens, and this is considered below (243). "..Participation is political. - It is trying to involve people in decision making by elected representatives, or contesting or sharing the power of those representatives" (244). In Richardson's view, a number of features are means to participation, rather than characteristics of the phenomenon, eg. decentralised administration and more open and accessible government (245).
Power is said to be an important part of the analysis and definition of participation (246), and is integral to Arnstein's definition of citizen participation noted above. Leo Smith states: "All definitions of participation... express (or assume) a relationship between those with the power to take decisions and those who ought to have a right to influence them..." (247). The importance of recognising which people have power as a prerequisite to increasing participation has been stressed (249).

Participation has been described as involving "a modification... of the orthodox authority structure" (250) and, in the case of planning, as an "aspect of the class struggle" (251). Midgley refers to the empowering of disadvantaged peoples as an integral part of community participation in social development in third world countries. He refers to reports by the United Nations Research Institute for Social Development Popular Participation Programme, which state that "authentic participation requires... a "massive redistribution of power..."" (252). A number of writers conclude that increases in participation have not resulted in concomitant increases in power (253), and distinctions have been drawn, which will be considered below (254), between "false participation" or "pseudo participation" and "real participation". Richardson argues that the "incorporation of power into a definition of participation does little to aid understanding..." (255), and refers to difficulties in establishing the presence, extent and results of power, and variations in power in different instances involving participation. She states that assumptions about power should be formulated as hypotheses about the results of participation, rather than as part of a definition of the phenomenon (256). In Richardson's view, some writers have seen the views and goals of participating consumers and decision makers as either shared
or opposed, when both sides are likely to have some common, as well as opposing interests. "..Access and interaction between the groups involved should be a key dimension for a definition of participation - not power" (257).

Reference has previously been made to changes in some professional-client relationships in order to facilitate the participation of the latter (258). Some authorities highlight the importance of a reduction in power of the professional, with increased value attached to the contribution of the client working as an equal partner, with the professional "..treating consumers as resources and sources of authority.." (259). In health care, consumers' "taking on tasks normally done by professionals" is seen as an important component of participation (260). Ways in which professionals and their power may hinder participation have been described, e.g., their reluctance to give up power (261).

**TYPES OF PARTICIPATION**

A wide variety of types of participation has been described. Advocacy of a consumer's rights or needs may be undertaken by the consumer herself (self advocacy), by people with legal training (legal advocacy), or by lay volunteers (citizen advocacy) (262). The role of patients' advocates to represent the interests of patients in psychiatric hospitals in Holland, and more recently, in this country, has been described (263). Participation occurs both within established structures and in the setting up of alternatives. A number of methods of intervention in social work and psychiatry are probably more appropriately seen as
facilitators of, rather than types of consumer participation. These include contracts between clients and social workers, group work, community work and therapeutic communities (264). Participation has been described in a variety of British and American statutory and voluntary residential and day services for different client groups (265), and in poverty programmes and Community Mental Health Centres in the USA (266). Such participation can take the form of involvement in particular responsibilities or the making of decisions - e.g. as a management committee member, or by consumers taking on volunteer or paid employee roles. Other types of participation include the assessment, informal or formal, of consumer views and needs, and the involvement of consumers in the evaluation of services, the sharing of information and consultation of consumers by decision makers, and opportunities for consumers to make complaints or express opinions (267). The involvement of consumers and citizens in the making and implementation of decisions and policies has been described, and Richardson outlines some of the means by which this may be achieved. These include meeting with elected representatives or officials, public meetings, private discussions with decision makers, on an ad hoc or regular basis, membership of committees with varying powers, and involvement in seminars and conferences to present the consumer viewpoint (268).

Types of participation which have started outside established structures include some campaigning and pressure group activities and the formation of self help groups and other groups and services, of which the radical "patient-controlled alternatives to the mental health system" in North America are a notable example (269).
A number of writers have highlighted what they see as the most important features or types of participation. For Leigh, "...the main themes of participation are consultation; the production and sharing of information about plans and services; and the direct involvement with the professionals and councillors in the decision making tasks associated with planning and policy creation." (270). Webb suggests that participation can be classified into: representation of clients; quasi-judicial; consumerism, non official and official; consultation and client producer co-operation/collaboration (271). Dyer and McAusland and Brandon outline evaluation of psychiatric services according to Normalisation principles, which includes consumer participation in various aspects of hospital life (272).

DIMENSIONS OF PARTICIPATION

It was stated earlier that some critics comment that certain writers on participation fail to appreciate its complexity. It is argued here that the nature and characteristics of participation can best be understood by considering the following dimensions:

1. Different DEGREES of participation, from no or minimal involvement or influence, to complete control.

2. Different LEVELS of participation, from participation affecting only the individual consumer to participation at Central Government level.
3. The types of participant: eg. consumers, their relatives, citizens, and other people who are involved.

4. The mode of interaction, from close co-operation and agreement with decision makers, to strong opposition and conflict.

Degrees of participation

"It is difficult to create a typology of citizen participation without oversimplifying and muddling the issues. Rarely are there any "pure" patterns of participatory behaviour that can be neatly categorised..." (273). Despite these difficulties, several authorities have produced typologies of participation, which include varying amounts of involvement. Thus, Spiegel and Mittenthal’s typology of participation negotiation, shared policy and decision making, joint planning, delegation of planning responsibility and "neighbourhood control" (274). The typology of Brager et al includes "none [i.e. no participation], receives information, is consulted, advises, plans jointly, has delegated authority, and has control" (275). Several typologies of participation in industry have been produced, ranging from workers having little or no influence on decision to having complete control (276). Dinkel et al list "seven major categories of activities" representing varying degrees of citizen participation in Community Mental Health Centre evaluations (277).
- "Citizens as subjects (community or client surveys).
- Citizens receive evaluation information through the media or at open forums.
- Citizens review program goals.
- Citizens review evaluation findings.
- Citizens help plan agency evaluation.
- Citizens conduct evaluation independent.
- Citizens conduct evaluation independently or with the agency" (278).
**DEGREES OF CONSUMER INVOLVEMENT**

<table>
<thead>
<tr>
<th>DEGREE</th>
<th>TYPE OF CONSUMER INVOLVEMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOW 0 NIL</td>
<td>All decisions are made entirely by non-consumers, who do not explain their decisions to Consumers, or otherwise involve them in decision making. Clear distinction between consumers and non-consumers.</td>
</tr>
<tr>
<td>1 EXPLANATION</td>
<td>Non-consumers provide consumers with information, and explanation of their decisions, but do not otherwise involve consumers in decision making.</td>
</tr>
<tr>
<td>2 CONSULTATION</td>
<td>Non-consumers ask consumers their views and opinions, and take these into account when making decisions.</td>
</tr>
<tr>
<td>3 DIRECT REPRESENTATION</td>
<td>One or more consumers, representing consumer opinion, are actively involved in decision making.</td>
</tr>
<tr>
<td>4 EQUAL PARTICIPATION</td>
<td>Consumers and non-consumers are equally involved in decision making. Little or non distinction between &quot;consumers&quot; and &quot;non consumers&quot;.</td>
</tr>
<tr>
<td>HIGH 5 TOTAL RUNNING OF THE ORGANISATION</td>
<td>The organisation is run entirely by consumers, who decide whether or not to involve other people in decision making.</td>
</tr>
</tbody>
</table>

"TRUE AND "FALSE" PARTICIPATION"

Several authorities have distinguished between "true participation" and "false participation" or "pseudoparticipation". Thus, both Verba et al and Pateman use the latter term to refer to "techniques used to persuade employees to accept decisions that have already been made by management..." (279). The United Nations Research Institute for Social Development distinguished between authentic participation and pseudoparticipation, stating that the latter was "imposed from above" (280).

Chamberlin makes a distinction between real "patient-controlled alternatives to the mental health system" and those which are "false alternatives", failing to live up to their promises of true participation and equality (281). Parry uses the term "unreal participation", to describe situations where there is apparent "participation" in politics, but decisions have already been made (282). Several writers refer to "tokenism" (283): giving participation to someone as a gesture without then allowing him/her much influence.

One of the most elaborate typologies of degrees of participation is "Arnstein's Ladder", shown on page (fig 3.2). In this, the bottom two "rungs" manipulation and therapy, are classed as non-participation, rungs 3 to 5 (informing, consultation and placation) are degrees of tokenism; and only the top three rungs (partnership), delegating power and citizen control) are classed as degrees of citizen power (284).
ARNSTEIN'S LADDER OF CITIZEN PARTICIPATION

Citizen control

Delegated power

Partnership

Placation

Consultation

Informing

Therapy

Manipulation

Degrees of
citizen power

Degrees of
tokenism

Nonparticipation

Eight rungs on a ladder of
Citizen Participation

Richardson criticises "Arnstein's Ladder" and other typologies which distinguish between "true participation" and "pseudoparticipation" on several grounds. She argues that arrangements for participation do not "...necessarily lead to particular predictable results... the assumption ...that the impact of participation will necessarily be of a particular kind is unfounded... the process of bargaining which participation necessarily entails makes the result of ... discussions uncertain and unpredictable..." (285).

Participation has been described as occurring at different stages of policy making or policy implementation. Cook, citing Deakin and Willmott, refers to participation in "strategic planning, the planning of service provision, delivery of services and feedback" (286). Windle and Cibulka describe participation in different policy stages: authorising, enabling, planning, governing, service giving and programme evaluating (287). There has been a number of descriptions of the development of participation, particularly in community work (288). Such development often consists of participants beginning to identify issues about which they feel strongly, and gradually increasing their attempts to influence policy making (289). Some authors have identified methods of achieving participation. E.g., Bidwell and Edgar describe four models of providing planning aid: advice (least effective), advocacy, adult environmental education, and community development models (most effective) (290).
LEVELS OF PARTICIPATION

Surprisingly, the literature review failed to reveal any typologies of participation which represent different levels of the phenomenon. The term "level" is used here to describe the extent of participants' attempted or actual influence: from participation by a client or patient in decisions which affect her/his care to policy making at Central Government level.

Specific references in the literature to levels of participation also appear to be limited. Boaden et al point out that participation in Social Services can create benefits for individuals, but that this rarely leads to a "wider policy impact beneficial to all clients" (291). Windle and Cibulka refer to impacts of participation on political, organisation and service levels (292). Shields comments: "patient participation can be encouraged at various levels. Patients...can be involved in choosing and executing a course of treatment; life on psychiatric wards can be influenced by ward community meetings; at a higher level, patients can be consulted and involved in deciding overall policies and planning services." (293). Some authorities have examined participation specifically at the individual level, within the doctor/patient relationship. Szasz and Hollender distinguished between: activity-passivity, with the patient playing a passive role without active participation in
her/his treatment; guidance - co-operation in which the doctor is seen as knowing best, and the patient carries out medical instructions; and mutual participation, in which "the doctor helps the patient to help himself" (294). Freidson suggested the addition of other categories in which the patient takes the leading role in influencing treatment initiatives (295).

The "level" at which participation occurs does therefore seem to be of a priori significance, and a simple typology is not difficult to specify (Fig. 3.3. page 77). In this typology, the first level is limited to the individual: her/his participation, within a professional - consumer relationship, in the care, services or treatment which (s)he receives. The next level concerns participation which affects a small number of other, local, consumers. Examples include self help groups, involvement in other local voluntary organisations, and participation in residential homes and hostels, day centres and psychiatric wards. Level 3 participation is concerned with the running of large institutions, e.g., a comprehensive school or hospital, or participation in a social services or planning sub-committee. Levels 4, 5 and 6 refer to participants' attempted or actual influence at Local Government, Regional and Central Government levels respectively. Figures 3.3 (p 73) illustrates this typology of levels of influence (296).
<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>CENTRAL GOVERNMENT. Individual has attempted or actual influence on Central Government policy making, e.g. through committee or commission membership, or lobbying MPs. Participation may be through membership of a national voluntary organisation.</td>
</tr>
<tr>
<td>5</td>
<td>REGIONAL. Individual participates in bodies concerned with a Region, eg. Regional Health Authorities. Membership of Regional Committees of National Voluntary Organisations.</td>
</tr>
<tr>
<td>4</td>
<td>LOCAL GOVERNMENT. Individual involved in local statutory main committees or in attempts to influence Local Government Councillors or officials. Participation in District Health Authorities and other bodies at District level.</td>
</tr>
<tr>
<td>3</td>
<td>LARGE INSTITUTIONS/LOCAL STATUTORY SERVICE SUBCOMMITTEES. Individual participates in decision making in large institutions or in statutory service subcommittees.</td>
</tr>
<tr>
<td>2</td>
<td>SMALL GROUPS/INSTITUTIONS. Individual participates in decisions affecting others in a small self help group, voluntary organisation, small institution or ward.</td>
</tr>
<tr>
<td>1</td>
<td>INDIVIDUAL. Individual participates in decisions affecting herself/himself.</td>
</tr>
<tr>
<td>0</td>
<td>NO PARTICIPATION/INFLUENCE AT ANY LEVEL.</td>
</tr>
</tbody>
</table>
TYPES OF PARTICIPANTS

Few typologies of participation seem to have included types of participants. Windle and Cibulka include a participant dimension to their multi-dimensional typology (297), and divide participants in community mental health centres into "communities", "citizens", "employees" and "consumers" (298). Brager et al refer to four categories of participants in community groups, with varying amounts of involvement and commitment (299), and Richardson and Goodman distinguish between involved and non-involved participants in self help groups (300).

MODE OF INTERVENTION

This term, used by Brager et al, refers to the relationship between consumers or citizens and decision makers (301). Participation may take the form of collaboration, co-operation, integration on the one hand, or conflict, disruption or opposition on the other (302). Brager et al distinguish between "partnership with a governmental unit as well as against it" (303) and participation in a service or participation against it" (304). These authors produce a list of "modes of intervention", with particular tactics used:
<table>
<thead>
<tr>
<th>Mode of Intervention</th>
<th>Tactics</th>
</tr>
</thead>
</table>
| Collaboration                        | Problem solving  
                                   | Education                           
                                   | Joint action                           
                                   | Persuasion                             |
| Campaigning                         | Political manoeuvring  
                                   | Bargaining                           
                                   | Negotiation                           
                                   | Mild coercion                          |
| Contest or disruption              | Clash of position in accepted social norms. Violation of normative behaviour. Violation of legal norms. |

Distinctions have been made between Community Development and Community Action as techniques for participation which represent consensus and conflict, respectively. (305).

"...Community development is a process which aims to achieve change through consensus. Community action uses conflict to achieve change. The worker aims to verbalise discontent, articulate grievances, to form a pressure group with which to confront authority in a militant struggle." (306).

Warren distinguishes a number of differences between Citizen Involvement and Citizen Action involving people in poverty. In the former, consumers work with the official organisation, which defines the nature of participation, and attitudes towards professionals are favourable. In Citizen Action, participants are adversaries of the official agency, hostile towards professionals, and involvement consists of "requests, demands, threats and acts of disruption, attacks on the target organisation's legitimation" (307). In Citizen Involvement "successful" citizen participation consists of what are seen by the official agency as "responsible" suggestions, which can be put into practice without causing problems to the agency. In Citizen Action, "successful" citizen participation is equated with citizen control (308).
Holland describes three models of Community Action Agencies in the USA. These bodies were set up by the Office of Economic Opportunity in the late sixties and early seventies to initiate programmes involving participation to ameliorate poverty. Most Community Action Agencies ran according to a co-operative model, and few used conflict or community control models (309). "..Militant Community Action Agencies, faced with the threat of withdrawal of funds...found it necessary to compromise with existing institutions in order to survive." (310).

Richardson criticises a tendency to view participation as either "..a vehicle solely for co-operation on the one hand, and solely for conflict on the other..." (311), and suggests that consumers and service-providers may both have shared interests or concerns and disagreements (312).

**A MULTI-DIMENSIONAL MODEL**

Most typologies of participation appear to have used only one dimension. Windle and Cibulka propose that this is misleading, as "...depending on which defining elements one emphasises, the concept can be viewed quite differently..." They add "...much of the disagreement about this concept is rooted in different value preferences which cause persons to stress some dimensions to the exclusion of others..." (313). Windle and Cibulka propose a three-dimensional model as a means towards better understanding of participation, with incorporation of power, functional and participant dimensions. Fig 3.5, illustrates the model of Windle and Cibulka (p 34).

This chapter will close with the consideration of two multi-dimensional models which, it is proposed, could be used to illustrate and understand
consumer participation in voluntary organisations for mental health. The first model (Fig. 4.6, p 85) is based on that of Windle and Cibulka (314), and illustrates three dimensions which, it is suggested, particularly need to be considered in attempts to study consumer participation in these organisations. These dimensions are:

a) **degrees of participation:** the amount of opportunities for involvement and influence of consumers;

b) **levels of participation:** from individual to Central Government;

c) **types of participants:** eg. consumers, their relatives, interested laypeople, mental health professionals.

In this model, the degrees dimension follows the typology given on page 79, based on that of Brager et al (315); whilst the levels dimension is based on the typology on page (Fig 3.3) (77). As with the model of Windle and Cibulka, it would be possible to compare voluntary organisations on the three dimensions by shading in particular cubes to represent their degree(s) and level(s) of participation and their main participants. The comparison of voluntary organisations according to levels and degrees is further considered in Chapter 15 (316).
Finally, Fig. 3.7 represents five dimensions of participation, including modes of interaction, and types of participation, as well as degrees, levels and participants. Voluntary organisations could be plotted on each dimension on this figure. It is suggested that organisations with a line on the edge of the figure would be likely to be more radical than those with lines near the centre. However, the relationship between the five dimensions is unlikely to be clear-cut. Thus, a voluntary membership may have a mainly oppositional mode, and consumers in a self-help group may have considerable influence on decisions affecting themselves and their group, but no influence on wider society.

These three-dimensional and five-dimensional models are presented here as heuristic devices: attempts to begin to better understand participation in voluntary organisations for mental health, and MIND in particular. Data from the field research in the present study suggests that consumer participation also involves three other components which receive little or no consideration in the literature. These include the extent to which participation is covert or overt ("openness"); conscious or unconscious ("consciousness"); and formal or informal ("formality"). These components are considered later in this thesis (317). The concluding two chapters include the presentation of a model which incorporates openness, consciousness and formality, and further consider typologies of participation (318).

The next two chapters describe the development of MIND, and the growth of consumer participation in the voluntary movement for mental health.
Figure 3.5
Three-Dimensional Model of Participation of Windle and Cibulka

Adapted from: WINDLE, C. and CIBULKA, J. G., 1981. Figure 1 in "A Framework for Understanding Participation in Community Mental Health Services", Community Mental Health Journal, Vol. 17, No. 1, p 41.
Figure 3.6
Three-Dimensional Model Illustrating Levels and Degrees of Participation and Types of Participant
Figure 3.7
Five-Dimensional Model Representing Dimensions of Participation

- **Types of Participation**
  - NIL
  - Traditional "Helping"
  - Doing Things for Consumers
  - Advocacy
  - Campaigning
  - Innovation

- **Modes of Intervention**
  - Opposition
  - Both Co-operation and Opposition
  - Close Co-operation with Authority
  - NIL

- **Degrees**
  - NIL
  - Explanation
  - Consultation
  - Direct Representation
  - Equal Participation
  - Total Decision Making and Responsibility of Consumers

- **Main Participants**
  - Consumers
  - Relatives of Consumers
  - Interested Laypeople
  - Mental Health Professions

- **Levels**
  - NIL
  - Individual
  - Small Group or Institution
  - Large Group or Institution
  - Local Government
  - Region
  - Central Government
On 25th November 1946, three voluntary organisations for mental health amalgamated to form the National Association for Mental Health (NAMH), later MIND. The merger had been inspired by members of two of the organisations, the National Council for Mental Hygiene and Child Guidance Council, who had been concerned about the overlap in services and functions of voluntary organisations concerned with the welfare of people with mental health problems and learning disabilities. They were joined by a third organisation, the Central Association for Mental Welfare (1).

This quest for co-ordination in voluntary services was not new. The Charity Organisation Society had been set up in 1869 to co-ordinate various kinds of charitable works (2). The origins of the Central Association for Mental Welfare can be traced back to the creation, in 1876, of a Charity Organisation Society sub committee to investigate provision for people with learning disabilities. This subcommittee later became the National Association for the Care of the Feebleminded, and was then replaced in 1914 by the Central Association for Mental Welfare, which provided community care and other services for people with learning disabilities, campaigned for legislative changes, and ran training courses for professionals (3). Local Associations for Mental Welfare were affiliated to this national organisation.
In 1918, the National Council for Mental Hygiene was set up in Britain by Maurice Craig, an eminent psychiatrist, as part of a world wide mental hygiene movement. Its main concerns were providing training courses for mental health professionals and public education (4). The Child Guidance Council was founded in 1927 to encourage the setting up of services for children with emotional problems, or mental illness, and their families. It aimed to demonstrate examples of good practice in its own child guidance clinics, and worked with statutory bodies in the setting up of Local Authority clinics. Other functions included public and parental education, research and professional training (5).

In 1936 the National Council for Mental Hygiene and the Child Guidance Council set up a Committee to consider the restructuring of voluntary organisations for mental health, and invited the Earl of Feversham to be its chairperson. He was asked to "prepare a report which shall embody suggestions for eventually bringing together on a national basis all the voluntary mental health services in the UK" (6).

The Feversham Report, published in 1939, reported gaps in voluntary provision in some areas, and overlap in the work of voluntary organisations in others. One of its main recommendations was the establishment of a new national voluntary organisation for mental health, to incorporate the Mental After Care Association, the Central Association for Mental Welfare, the National Council for Mental Hygiene and the Child Guidance Council and to co-ordinate their work (7).
In January 1939 members of these organisations (with the exception of the Mental After Care Association) formed a Mental Health Emergency Committee in response to considerable national concern that the anticipated War would result in mental illness and stress reactions on a large scale (8). Out of this committee was formed, in 1943, the Provisional National Council for Mental Health (9). Throughout the War, Committee and Council worked closely with Central Government and Local Authorities, helping children and adult civilians with learning disabilities or mental illness, and later providing aftercare for people discharged from the Forces for psychiatric reasons (10).

The formation of the National Association for Mental Health did not signal an immediate change of direction. In the late forties and early fifties, it continued much of its constituent organisations' work in providing educational courses for professionals, public education and social services. The latter included advice and casework, several homes and hostels, mostly for children and adults with learning disabilities, and two approved schools. Moreover, the number of services provided by N.A.M.H. did not decrease until the mid seventies (11), but in 1956 the chairperson, Lord Feversham, could already comment that:

"...the most remarkable feature of the Association's development has perhaps been its move away from the provision of services towards a concentration on educational programmes both for professional people and the man in the street." (12).
In its early years, the National Association seemed to make little use of the popular media to promote public interest in mental health issues. This changed following the appointment, in 1955, of a Public Information Organiser and the setting up of a Public Information Committee, which aimed to achieve "... the dissemination of knowledge of conditions in mental health services ... the provision of an information service to the press on mental health matters and the stimulation of local groups." (13). One of the Association's earliest campaigns took place in 1960, with the launching of a "Mental Health Week", with the slogan "Mental Health is Everybody's Business". This attracted the support and co-operation of Central Government Departments and the churches, and some press publicity (14).

THE STRUCTURE AND ORGANISATION OF N.A.M.H./MIND

Since its inception in 1946, MIND has always had a national office in London, and by late 1985 it had seven regional offices (15) and 192 Local Associations (16), the latter being independent charities, each serving a local area, usually a town or borough, and affiliated to the national organisation.

During the nineteen sixties, N.A.M.H. attempted to further awaken public interest through the establishment of more Local Associations. Several Local Associations of the Central Association for Mental Welfare had become affiliated to the National Association in 1946, but few new Local
Associations were started in the fifties (17). The number of Local Associations increased considerably in the sixties, following the appointment of a Local Associations Officer. (See Table 4.1 p.) (18).

For a few years after World War Two, N.A.M.H. continued the work of the regional offices which had been set up during the war by the Provisional National Council for Mental Health at the request of Central Government (19). The last of these offices was closed in September, 1951, when the Association's regional work was taken over by Local Authorities (20). The first of the new regional offices was opened in Leeds in 1954, but further regionalisation did not occur until the mid seventies, by which time the number of local associations had passed the three figure mark (21).
<table>
<thead>
<tr>
<th>YEAR</th>
<th>NUMBER OF REGIONAL OFFICES</th>
<th>NUMBER OF LOCAL ASSOCIATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1947</td>
<td>12</td>
<td>Not recorded</td>
</tr>
<tr>
<td>1952</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td>1956</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>1960</td>
<td>1</td>
<td>26</td>
</tr>
<tr>
<td>1964</td>
<td>1</td>
<td>50</td>
</tr>
<tr>
<td>1968</td>
<td>1</td>
<td>66</td>
</tr>
<tr>
<td>1972</td>
<td>1</td>
<td>91</td>
</tr>
<tr>
<td>1975</td>
<td>2</td>
<td>126</td>
</tr>
<tr>
<td>1978</td>
<td>3</td>
<td>150</td>
</tr>
<tr>
<td>1980</td>
<td>5</td>
<td>161</td>
</tr>
<tr>
<td>1981</td>
<td>5</td>
<td>164</td>
</tr>
<tr>
<td>1982</td>
<td>6</td>
<td>168</td>
</tr>
<tr>
<td>1983</td>
<td>5</td>
<td>170</td>
</tr>
<tr>
<td>1984</td>
<td>5</td>
<td>179</td>
</tr>
<tr>
<td>1985</td>
<td>7</td>
<td>192</td>
</tr>
</tbody>
</table>

MIND has always had a royal patron, at present H.R.H. Princess Alexandra, and several distinguished vice patrons. In 1985, the organisation's Advisory Council included DHSS and Welsh Office representatives, and a large number of Local Authorities, political parties, professional associations and voluntary organisations(22).
MIND is governed by a Council of Management, to whom the National Director is responsible. During the period of fieldwork, the Council of Management comprised a chairperson, vice-chairperson and honorary treasurer, with 18 ordinary and six co-opted members, and was "...responsible for the overall managing of the affairs of the Association". In 1984 to 1985, National MIND had five departments (Appeals, Community Development, Legal, Publicity and Information, and Training and Education) and the Campaigns Unit, each headed by an Assistant Director who was responsible to the National Director. The Chief Accountant, and some other staff, were responsible to the General Secretary who was the second most senior staff member. Other staff were responsible to an Assistant Director. Each regional office had a Director with responsibility to the National Director and a Regional Advisory Committee which acted in an advisory capacity, and was not part of the formal decision making structure.

Appendix 3 lists the Aims and Objectives of MIND which were unchanged between 1974-5 and 1985-6. During the period of fieldwork, the main work of the organisation included:

1. Facilitating the implementation of community care services for people with mental illness.

2. Legal advocacy of consumers' rights, needs and views.

3. Providing information, advice and counselling and a welfare rights service.
4. Training and education of professionals.


6. Campaigns on specific issues: (e.g. on people with mental illness in prisons; minor tranquillizers dependency and prescribing; discrimination against people with disabilities).

7. Submission of evidence to Central Government on a variety of issues, including welfare benefits and homelessness.

8. Research on community care, prevention, and police powers under the Mental Health Act 1983.

9. Production of magazines and other publications.

10. Fundraising, and attempts to increase membership of the organisation.

11. Work with Local MIND Associations.

The Community Development Department's functions included facilitating the setting up of new Local Associations in the South East of England, housing development work, providing Local Associations with information, answering their requests, and considering their applications for money from various funds. This Department was disbanded in late 1985, and most of its work was transferred to a newly established Regional Office for South East, England.
During the period of fieldwork, there was concern to increase consumer involvement in National MIND, and to make the organisation more attuned to the mental health needs of women and of members of black and minority ethnic groups (28).

Responses from interviews suggested that the function of Regional Offices resembled a description given in the Annual Report of 1980 to 1981:

"Regional staff develop national policies and initiatives in their own areas - and feed back to MIND central office the vital information on which so many of these policies are based. They support Local Associations at the grassroots - and act as a bridge to the national organisation ... each Regional Office establishes its own particular projects and schemes in response to local needs." (29).

During the period of fieldwork there was considerable variation amongst the work of Local Associations. Most provided services, including social clubs, drop in centres, day centres, group homes, hostels and other accommodation. Other functions included advice, counselling and information services, public education, campaigning and fundraising. Each Local Association was run by an Executive Committee, consisting of officers and members, and some Associations employed staff.
From its earliest days, NAMH continued its constituent organisations' attempts to influence Central Government Policy. Over the years, the National Association was invited to submit evidence to a variety of Government Committees. It was often critical of Central Government policies, but its campaigning and lobbying were usually restrained. "It was all very polite", said one respondent, looking back to her early days in the organisation in 1963, whilst a former chairperson of the Council of Management said that about this time, NAMH had been more concerned to serve professional interests, rather than those of consumers and public. She commented that in the mid sixties the organisation was characterised by "ladies in hats making things nice." (30).

According to Anderson and Anderson, from 1964, the Association became gradually more critical and more investigative (31). This is perhaps reflected in the view of one respondent, a Vice Patron of MIND, who commented on changes within the organisation between 1958 and 1968.

"I think it became a little bit more strident and the pressure group aspect of its work seemed to sharpen up during that time."
(Interview. Vice Patron).

For many years, NAMH had supported the psychiatric view of mental health services fairly uncritically (32). A felt need for change in this respect is reflected in the Council of Management's comment in 1966:
We have, in our anxiety not to do harm, remained silent, or at least discreet, about conditions which we knew to be bad... they will be remedied only if public indignation about them is vigorously aroused." (33).

In the late sixties, the NAMH and the National Society for Mentally Handicapped Children (34) sponsored three Mental Health Weeks which aimed to involve the public in mental health issues, and to highlight deficiencies in services. (35). It is unclear why MIND's stance became more critical during the sixties, but this may have been a reflection of the general cultural climate at a time when authority was being increasingly questioned by some sections of society (36).

According to Mary Applebey, NAMH's first General Secretary and National Director, "... it was not so very large a step from the campaigns of the sixties to the MIND campaign of the seventies." (37). This three year campaign, conducted by the organisation's Campaigns Director, David Ennals, further spotlighted inadequacies in services, and included considerable lobbying of Central and Local Government (38), reports produced by the organisation, and many features in the media (39). This, the largest and most assertive campaign so far undertaken by NAMH, highlighted a change of emphasis in its work:

"... The Council of Management has decided that the Association's name should be changed from the NAMH to MIND. This is ... an acknowledgement that the true centre of the true centre of the Association's work has shifted from being a service organisation towards being a lobby." (40).
This change in emphasis was reflected in a review of MIND's policies in 1974, when it was decided that three of the organisation's residential services should be transferred to other voluntary organisations; and that future projects would be "pioneering, innovative and experimental" (41).

**THE LEGAL RIGHTS ERA**

In the mid and late seventies, MIND conducted further campaigns, related to inadequacies in provision for people with mental illness and learning disabilities, which attracted publicity and some political support. (42). But it was the organisation's campaigns related to mental health legislation and legal rights which were most in the public eye. Such campaigns between 1975 and 1981 were inspired largely by Tony Smythe who became the organisation's second National Director in 1974, and Larry Gostin who joined MIND's staff in the same year, and later became its Legal Director (43).

"...These appointments heralded a radical shift in both the objectives and the style of MIND: one of the organisation's primary concerns became the reform of the Mental Health Act 1959 in order to increase the rights of compulsorily detained patients." (44).

A working party was set up in October 1974 to examine the need for changes in mental health legislation and Larry Gostin was asked to prepare a
report for the DHSS (45). Many of the recommendations in this report were embodied in provisions in the Mental Health Act 1983 (46). Larry Gostin also provided legal and welfare rights advice to users of mental health services and their relatives and to mental health professionals and lawyers (47). Publications were produced to inform consumers about their rights in relation to mental health law, professionals received training in this area and evidence was given to various Central Government Committees. In 1977 MIND started "a representation service for patients appearing before Mental Health Review Tribunals" (48).

Much publicity, and not a little controversy, was generated by MIND's use of Test Cases to bring about change in mental health legislation. Some cases were brought to the European Court of Human Rights, in 1974 to 1975 and 1981 to 1982, as contravening Articles of the European Convention. In some cases a ruling was given in applicants' favour, and this too helped to bring about legislative changes (49).

MIND's legal campaigns attracted some support, but were also criticised by some Local Associations and by many psychiatrists, including a number who resigned their membership of the organisation, sometimes making public their reasons for doing so (50). MIND's work in relation to Special Hospitals was opposed by some Trade Union members; and the publicity which the organisation gave to allegations about Broadmoor Hospital incurred criticism from the Secretary of State for Social Services (51). In 1980, an MP, whose constituency included Broadmoor, made several allegations about MIND in the House of Commons, which generated much unwelcome publicity for the organisation (52).
At about this time, Tony Smythe commented that the publicity given to certain aspects of MIND's campaigning and legal work "... created an image of MIND and its preoccupation which does not necessarily truly reflect the variety and balance of the totality of our work for mental health." (53). Martin comments that, during the seventies, the organisation's range of work became narrower (54), but under Tony Smythe's directorship, this actually expanded considerably at regional and local levels. Five more Regional Offices were opened, and the number of Local Associations increased considerably: from 91 in 1972 to 161 in 1980 (55). The rise in Local Associations appears to have been partly related to two factors: the employment of regionally based staff to develop local initiatives; and the increased concern of local statutory services to fund and support the development of voluntary organisation services during a time of increasing financial constraints.

From the mid seventies, the number of Local Association services, and staff employed by them, rose considerably (56). At National level, other work of importance included a child advocacy service, the continued and increased provision of a general advice and information service and a variety of courses for professionals (57).

**MIND's MAIN AIMS IN 1980**

Members of MIND's National Staff and Council of Management were asked if they could compare MIND's main aims at the time of interview (June to October, 1985) with those of five years previously (towards the end of Tony Smythe's period as National Director). Their answers did not indicate "the variety and balance" of work described by Tony Smythe.
Thirteen out of 23 National MIND staff, and five out of six Council of Management members who were asked this question felt able to give an answer, usually based on their own experience, or in a few cases, on their impressions of MIND in 1980. Table 4.2 indicates the number of times particular aims of the organisation were mentioned by respondents (58).

**Table 4.2 The Main Aims of National MIND in 1980**

<table>
<thead>
<tr>
<th>Main Aim</th>
<th>Number of Respondents mentioning Main Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Legislation/legal work</td>
<td>8</td>
</tr>
<tr>
<td>Legal Rights</td>
<td>6</td>
</tr>
<tr>
<td>Publicity</td>
<td>3</td>
</tr>
<tr>
<td>Lobbying</td>
<td>2</td>
</tr>
<tr>
<td>Other &quot;Main Aims&quot; mentioned</td>
<td>3</td>
</tr>
</tbody>
</table>

The majority of respondents saw "mental health legislation", "legal work" and/or "legal rights" as MIND's main aim in 1980. Only six respondents mentioned other main aims (59).

At the time I started...around four years ago...reform of mental health legislation was not all that MIND was doing - but people saw it as the most important".

(Interview. Assistant Director, National MIND).

"...Five years ago, mental health legislation was uppermost in everyone's mind. Civil rights issues were much more to the fore".

(Interview. Assistant Director, National MIND).
One respondent felt that:

"On paper, all aims of MIND were equal, but the only thing that mattered was the Legal Department. Departments were cut to fund the Legal Dept."

(Interview. National MIND staff member)

This view was not expressed by other respondents although a Council of Management member felt that:

"..the emphasis at National level was on MIND as a lobbying group.. the voluntary service giving started to be pooh-pooed and seen as humdrum, good works - the real thing was to influence policies.."

(Interview. Council of Management member)

A NEW ERA FOR MIND?

The Mental Health (Amendment) Act was passed in October 1982 (60). Whilst MIND's chairperson at that time saw this as beginning "..a new era for MIND.." (61), during the next three years there appears to have been a
change of emphasis in MIND's work. Campaigning, legal work, advice and information, training and education and the development of regional work and of local associations, continued to be important areas of work. But the content changed, and moreover, some Departments began to undertake projects in areas in which MIND had previously had little involvement. This included work on dependence on minor tranquillizers and research on prevention and on the private sector (62).

Between 1982 and 1985, the Legal Department took on a considerably increased amount of individual casework, and became concerned with "a wider range of issues" (63), including welfare rights, the rights of people with mental illness in prisons and in Special Hospitals, the submission of evidence to various Central Government committees and work involving the implementation of the new Mental Health Act. The volume and scope of the work of the Legal Department increased but possibly attracted less publicity. According to MIND's Chairperson of the time, the focus of its work had moved from campaigning for change in mental health legislation "towards the less dramatic but nevertheless, vital, issues of community care." (64). A few respondents commented on the change of emphasis or direction in the organisation:

"...Five years ago.. civil rights were much more to the fore. I'm not saying they are not there now - but MIND has moved in a more practical direction...".

(Interview. Council of Management Member).
"...Probably five years ago there was more emphasis on the rights of patients... I think this is still important, but when Larry Gostin and Tony Smythe were here, there was a slightly different emphasis".

(Interview Legal Department staff member).

From the fifties, the National Association had pointed out deficiencies and gaps in Community facilities and had campaigned for improvements, but the early eighties saw an increased priority for this work. In the Autumn of 1982, Chris Heginbotham (who became National Director in August 1982, following Tony Smythe's resignation) initiated several policy working groups, including one whose work led to the production of "Common Concern". This "manifesto for a new mental health service" (65) contained recommendations for the setting up of comprehensive community mental health services to meet the felt needs of consumers and other members of local communities (66). A sequel to "Common Concern" suggested ways of implementing the recommendations in the manifesto.

Many of National MIND's other concerns, including campaigning, related to this work on Community Care, including an increase in work on the needs of people, who had been diagnosed mentally ill, for adequate accommodation, employment, and welfare benefits; and on adequate community facilities for specific groups, such as people dependent on minor tranquillizers and people said to need care in secure environments (67). Training and Education staff stated in interviews that much of their work with statutory professionals concerned the development of community facilities geared to the needs of people using them.
MIND's work on the development of community mental health services involved the organisation at national, regional and local levels, with some regional staff and statutory funded development officers facilitating Local Associations and working with Health and Social Services to plan and implement community based services (68).

While the comments of some respondents suggest that the focus of MIND's work broadened between 1980 and 1985, the new National Director in fact made efforts clearly to delineate policies and priorities, and to set limits on the work of the organisation. In 1982 he initiated a policy committee for this purpose, and several working groups were set up (69). A staff policy conference held in March 1984, agreed six working priorities for the next few years, which were subsequently agreed by Council of Management. These concerned "...the needs of people most severely disabled by mental illness... alternatives to hospital and the development of comprehensive local mental health services... matters relating to care and treatment... aftercare... [monitoring] the implementation of the Mental Health Act 1983 and similar legislative and legal rights issues" and "discussion with other agencies the needs of elderly people" (70).
A WIDER RANGE OF AIMS

It is hardly surprising, then, that a much wider range of aims were mentioned by respondents with respect to 1985 (Table 4.3) compared to 1980 (Table 4.2) (71).

TABLE 4.3

"Main Aim" | NUMBER OF RESPONDENTS MENTIONING ITEMS AS MAIN AIM
---|---
Campaigning | 9
Influencing mental health service provision | 9
Developing community mental health services | 8
Legal issues | 6
Welfare rights/anti-discrimination | 5
Training, and other work with professionals | 5
Tranx Campaign | 4
Work concerning people with mental disorder in prisons and other secure provision | 3
Provision of services | 3
Others | 8
Respondents also referred to changes in emphasis, or style, when comparing the organisation in 1985 with the MIND of 1980. One respondent commented that, in the earlier period “MIND had a reputation for being hard” while another commented favourably on the “forceful aggression of the Larry Costin and Tony Smythe era”. Three National MIND staff felt that in 1985, MIND had a lack of direction or communication and unity or purpose:

“..Since 1980 I think MIND has lost direction - no real focus..”

“..Poor communication means a lot of work duplicated.. a lack of organic unity in MIND.”

“..I think the organisation is drained of purpose, which it was not in Tony Smythe’s day.. lots of talk about aims, but they are not being pursued..”

(Interview. National MIND staff).

Three other respondents indicated that they welcomed changes in style or emphasis:

“..MIND is much more aware of the model it hope to develop, rather than being an iconoclast.”

“..I think the present aims of MIND are much wider and less dogmatic.. MIND has come.. much more into line with the avowed aims.”
"...Compared with 1980... MIND talks out in a way which is balanced, informed and not so dramatic. MIND has come out of adolescence..."

(Interview. National MIND staff).

Work planned for the late eighties included further campaigning for the development of comprehensive community mental health services, and for "positive rights to care, support and treatment" (72). Concern for the rights of users of mental health services had widened from a focus on legal issues to matters concerning service provision. One respondent commented:

"...Five years ago there was a much heavier emphasis on legalism and development of a legal framework. We've moved towards a reconciliation of a legal framework of service entitlement and a civil libertarian model...".

MIND literature, interviewing and participatory observation provided data which suggested that there was increased interest in consumer involvement within MIND in the mid nineteen eighties. The next three chapters examine the nature and extent of consumer involvement in the organisation, particularly at this time.

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By the nineteen eighties, MIND had become a complex organisation, with the beginnings of consumer participation, (referred to as "consumer involvement" by most MIND participants.) In short, using Gerard's approach to the norms governing relationships between participants in voluntary organisations (1), MIND appeared to be moving towards reciprocity (mutual giving and receiving of help) and solidarity (collective action), and away from the beneficence which had characterised the organisation, and indeed, most voluntary services, until the nineteen sixties (2). Gouldner describes reciprocity as "..sustaining mutually beneficial exchanges between individuals and groups, and.. beneficence [as] governing personal responsibilities to those in need.." (3). Gerard states that in voluntary organisations, solidarity extends into political activity and:

"..involves identification with, and a sharing the reality of the poor in some demonstrable sense, is related to notions of equality and self determination, and emphasises social and political action.. [and] eliminating the social distance between the parties involved." (4).
An examination of apparent changes in MIND's value system follows later in this chapter, as this is crucial to understanding how the organisation became more committed to consumer involvement in the nineteen eighties. To explain this more fully, it is first necessary to explore MIND's historical roots.

In the eighteenth and nineteenth centuries, a number of people who had been inmates in madhouses and asylums published accounts of their experiences of appalling conditions (5), and a few such people were involved in attempts to effect reforms, eg. through the Alleged Lunatics Friends Society (6). However, from the Middle Ages until well into the twentieth century, most voluntary efforts for mental health were characterised by beneficence, with the donor in a superior position to the recipient (7). Despite such charity, and some enlightened attitudes, eg. of certain medieval and Renaissance physicians (8), people with mental illness were often perceived as having no more reason than animals, and were often objects of fear or ridicule (9). Such attitudes were not associated with concern to consider their needs and views (10), although greater interest in the consumer perspective was shown by the (predominantly lay) reformers who implemented principles of moral management in certain institutions in the late eighteenth and early nineteenth centuries. Moral management emphasised the sharing of activities by inmates and staff, compassionate care and the provision of occupations appropriate to the inmate's social class (11).
In the early nineteenth century, voluntary efforts in asylums included a beneficent system of "lady visitors" who apparently saw themselves, in some respects, as superior to the inmates and many of the staff (12). However, in the second half of the nineteenth century, there was increasing criticism of indiscriminate charity and the encouragement of self help (13), with a shift in voluntary efforts for mental health from the charity of upper and middle class lay people to the increasing participation of the new professionals for mental health: psychiatrists and almoners with an interest in this area (14). The first voluntary organisation specifically for people with mental illness was the Mental After Care Association, founded in 1879 by the Chaplain of the Middlesex Asylum to provide accommodation and help to discharged patients. This was a professionally run organisation, with several psychiatrists involved (15). The Central Association for Mental Welfare, (which became one of the constituent members of the NAMH), and preceding voluntary organisations for people with learning disabilities, appear to have been run largely by politicians, professionals, and other (often influential) middle class and upper class people. Decisions about moves to reform legislation and care for people with learning disabilities seem to have been made largely on the latter's behalf, with few apparent attempts to assess whether or not any of them could express a view, or wished to do so. If committee members were involved because they had relatives with learning disabilities this was not explicit, and efforts do not appear to have been made to attract service users or their relatives to the organisation (16).
Much of the work of the Central Association for Mental Welfare was inspired by Evelyn Fox, a pioneering psychiatric social worker, who became the first Secretary of the Child Guidance Council (17). This organisation also appears to have been run by politicians, mental health professionals and other influential people (18).

The National Council for Mental Hygiene, started in Britain in 1918, owed its origins to Clifford Beers, who started the National Committee for Mental Hygiene in the USA in 1909, and later initiated a worldwide mental hygiene movement (19). Beers' enterprise was inspired by his determination to improve psychiatric services and influence professional and public attitudes towards people with mental illness, following his horrendous experiences as a patient in several mental hospitals (20). Beers' movement was characterised by beneficence, rather than solidarity or participation (21). He did not make particular attempts to attract other users of mental health services to his movement, but made considerable efforts to gain the support of many eminent people, including prominent psychiatrists, and other mental health professionals (22). The British National Council for Mental Hygiene was run almost entirely by mental health professionals, particularly psychiatrists, and had close links with the Tavistock Clinic. Members of the American Council for Mental Hygiene tended to provide services for people with mental illness, rather than doing so with them (23). In Britain, members of the public, including users of mental health services, appear to have had little involvement in the running of the National Council, or of the other two organisations which merged into the National Association for Mental Health (24).
In the late nineteen forties and fifties, there are few references in Annual Reports of the NAMH to consumers' or their relatives' views or felt needs, or to their involvement in running the organisation or its projects or services (25). The lack of such references does not necessarily indicate the extent of consumer involvement at this time, but it does suggest that NAMH did not see it as important to advertise itself as an organisation in which consumers or relatives took an active part in decision making.

According to Anderson and Anderson, it was not until the early sixties that "...the voice of the consumer was really heard within MIND..." (26). Some members of the National Association who were parents of children with learning disabilities, and particularly keen to make their voices heard, formed their own organisation in 1950, rather than remain within NAHM. (27).

INTEREST IN CONSUMER VIEWS

From the mid fifties there was growing concern in NAMH to understand the views of consumers, and their relatives, with an increase of literature for the latter. In the sixties the organisation published accounts by consumers and involved them in its publications and a television programme (28). The 1964 Annual Conference included tape recordings of relatives' descriptions of the inadequacies of services experienced by themselves and by mentally ill family members (29). NAHM's tentative move, from the mid sixties, towards a more critical stance, was influenced by this increased awareness of consumer and relative views (30).
According to Mary Applebey, reports on Annual Conferences "...show the emphasis moving gradually away from professional argument and towards an awareness of consumer demand." (31). However, one respondent felt that consumer and relative participation in Annual Conferences resulted at first in some embarrassment and criticism.

"...I can remember the embarrassment patently felt when a consumer asked a question, and I think that puts where the consumer was at this time [referring to the sixties and seventies]. I can remember the first conference when relatives...did a session... a great deal of criticism from the floor that that was putting them under unnecessary strain, when they wanted to express views."

(Interview. Council of Management member).

From the late sixties, there was increasing concern to represent consumer needs, but for many years the organisation continued to speak on behalf of consumers, rather than involving them in this representation, or facilitating self advocacy. This is possibly reflected in Annual Report descriptions of Local Associations. Whilst there are occasional references to consumer participation in Local Associations (32), many descriptions of their work suggests a model of volunteering in which "consumers" passively received help or services given by "non consumers". (33).
The MIND campaign of 1971 to 1972 emphasised consumer rights (34), and this concern intensified, and extended to include legal and civil rights, when Larry Gostin and Tony Smythe joined the organisation. Work in this area, between 1974 and 1985, involved advocacy by Legal Department staff, but was usually initiated by individual consumers (35), who took an active part in deciding what action to take. Some test cases were initiated by MIND staff, on behalf of consumers, and with their active involvement. (36). What is not certain is how far consumers wished to effect changes in mental health and other legislation, in addition to obtaining redress themselves (37).

Between 1975 and 1982 there are references in Annual Reports to consumer involvement in the running of a hostel (one of the last of National MIND's residential projects), and the active involvement of the local community, and of users, in a pioneering community mental health project, set up by National MIND and another organisation (38). The participation of people with consumer experience in the National office during the period of fieldwork is described in Chapter 6.

THE GROWTH IN SELF HELP GROUPS

During the seventies and eighties, there was a considerable growth in the number of self help groups, most of which were started by people with a particular problem or illness, and/or their relatives. These organisations aimed to provide mutual aid or support (39), and some grew into national
networks of self help groups. The latter included the National Schizophrenia Fellowship and the Fellowship of Depressives Anonymous, both founded in the early seventies, and the Manic Depression Fellowship which started in 1983 (40).

Many self help groups developed within MIND Local Associations from the late seventies to 1985, some of them initiated by regional staff. Other regional MIND projects which facilitated consumer involvement included one which promoted mental health in schools. This involved enabling pupils to share feelings and views. Staff in another region encouraged statutory service providers to evolve services which met consumers' felt needs, according to the principles of normalisation (41), and the Director of this MIND region conducted research on consumers' views and experiences of mental health services (42).

At the time National MIND dealt with an increasing number of enquiries from consumers and relatives which, according to Annual Reports and some respondents, influenced campaigns and the setting up of particular services, especially in the areas of welfare rights and minor tranquillizer dependency, and the production of publications on consumers' rights. MIND's magazines "Mind Out", and later "Open Mind", included many consumer views and experiences. A number of other MIND publications were written by, or in collaboration with, consumers (43).

Bender, speaking in 1982, suggested that "...the model developed by MIND is effectively the..type of leadership (the charity model), and that it is
moving towards an expertise model whilst being attracted by the participation model..." (44). This judgement accords with findings of the present study. In 1985 MIND was still, in some ways, a beneficent organisation, with upper class and middle class people, particularly politicians and mental health professionals, as its vice patrons and on its Council of Management (45). The organisation also continued to rely on the expertise of its professional workers, and also promoted, largely through its staff, the participation of people with consumer experience (46).

The following two chapters describe the extent and nature of consumer involvement in MIND, during the period of fieldwork, in national and regional offices and in two local associations.
CHAPTER 6

CONSUMER INVOLVEMENT IN NATIONAL AND REGIONAL MIND

The next two chapters describe the nature of consumer involvement in National and Regional MIND, and in two Local Associations which were studied in depth ("Eastvale" and "Westhill" MIND).

During early fieldwork, particularly in pilot interviews, attempts were made to assess the amount of consumer involvement in Local Associations e.g. by measuring various components on four-point rating scales (1). I started the research with certain assumptions about consumer involvement, including the belief that the term referred to participation in decision making and responsibility in MIND by those members who had experienced mental health problems and/or used mental health services (2).

As the research progressed, I became increasingly aware of the complexity of consumer involvement and its various components. For example, although Eastvale MIND had far more formal opportunities for participation than Westhill MIND, the latter Association was found, in some ways, to have as much consumer involvement, albeit of a more informal and unstructured nature (3).
As more data were gathered, I became increasingly interested in respondents' perspectives of the nature and meaning of consumer involvement, and more aware of my tendency to take my own meanings and values for granted.

Most of the study of National and Regional MIND was done after the fieldwork in Eastvale and Westhill MIND. As a result of my increased awareness of the complexity of consumer involvement, I decided to ask National and Regional MIND respondents for their views on the meaning of "consumer" and "consumer involvement". These questions were asked in order to increase understanding of the meaning and nature of consumer involvement in MIND. In retrospect, it would have added to the study to have asked these questions of Eastvale and Westhill MIND respondents (4).

This chapter describes participants' responses to these questions, and also considers the nature and extent of consumer involvement in National and Regional MIND, and the organisation's policies to increase consumer involvement at these levels. Material on these topics was collected in participant observation in National MIND, and in interviews with 59 people. These included nine volunteers, twenty three National and ten Regional staff members, ten members of the Council of Management, one Vice Patron and six members of Forum (5).
The use of the word "consumer" to describe a user of a statutory or voluntary service was outlined in Chapter 3. The term does not appear in MIND Annual Reports until the nineteen eighties, when it was used with increasing frequency (6). Respondents were asked: "In your view, which people are the consumers in relation to mental health services?" (7). A similar question had been posed by the National Director in his introductory address at a MIND Workshop on consumer involvement for Local Associations in 1985, and was debated by course participants (8). Uncertainty about the meaning of the term, and which people constituted consumers of mental health services was expressed (9). In interviews, respondents described "consumers" as users of particular services (33 respondents), people with experience of mental illness or mental health problems (14 respondents), relatives and/or friends of people with mental illness (13 respondents). Eight respondents felt that all people were potentially, or actually, consumers of mental health services (10).

Eight people referred to services in general terms: Comments included ".someone who at some stage.. has used the mental health services.." and ".people on the end of .. the services Local Associations.. or Health and Social services provide .. people in hospital, out-patients, tailing off to people who use GP services.." (11).

Nine respondents mentioned hospital services, but only one referred to social services. Five respondents included people who sought help from general practitioners. Only four respondents mentioned users of MIND services (12) and only one person referred to preventative
services (13). Two respondents included in their definition people who had benefited from services.

A Forum member commented that, in his Local Association, "...we have a relative support group... and we'd call those [relatives] consumers...", whilst a Regional Development Officer said she would "...include someone who's cared for someone with a mental health problem because they also... have been... involved with the psychiatric services..." The National Director commented: "The term consumer also covers relatives, friends and the local community - all are potentially consumers or carers of people with mental illness." (14). In contrast to these views, two respondents felt that the term "consumer" should be used mainly to describe people with mental health problems, rather than relatives. Two individuals commented on possible clashes of interests between these two groups. The Legal Director commented: "...His [the consumer's] (15) problems may affect...relatives, although from a Rights point of view... it is dangerous to see [relatives] as consumers..." Two respondents felt that mental health professionals could be classed as consumers, one of them adding that "they're often recipients of [mental health] services..." However, another respondent felt that, unlike some service users," staff may be devalued, but don't lose citizenship." (16).

Eight respondents felt that everyone was potentially or actually a consumer of mental health services, and a few other people referred to "others' beliefs that this was so. Two opinions were expressed
about who was the consumer in relation to MIND's work. A few respondents said that MIND's concern was the mental health of everyone, and that the whole population constituted "consumers" in this sense:

"..I would like to see the word consumer used in.. the way the Consumers Association used that term. All of us receive health care, and I'd sooner pitch at the population at large, rather than designated psychiatric patients. This is important because MIND calls itself the movement for mental health, and if you use that banner, you need to see mental health as affecting us all."

(Interview. Assistant Director)

"..MIND's concern is to be a consumer organisation: that everyone is a consumer of mental health services. MIND has attempted to be that since it was born."

(Interview. Regional Director)

Other respondents felt that MIND needed to concentrate attention on consumers with experience of mental ill health and mental health services.

"..I know there is a kind of liberal interpretation saying we're all potentially consumers. I don't take that definition..I think that a broad-based definition avoids the most difficult and intractable issues: basically to address policies of antidiscrimination for the people most discriminated against."

(Interview. National MIND Staff Member)
"I know there are different interpretations: "we are all consumers"... but I think it distracts from the main thrust of what MIND does."

(Interview. Staff Member, National MIND)

The views quoted above reflect two areas of MIND's work which are referred to in the Aims and Objectives of the organisation listed in Annual Reports and in MIND's Policy Priorities (17): the education of the general public about mental health and concern about the needs and rights of people with mental health problems and learning disabilities (18). The organisation's literature for the public has stressed the "normality" of mental health problems and the likelihood that "anyone" can become a consumer of mental health services:

"It's the most common form of illness today, but few dare to admit their suffering".

(19)

"One in six women and one in nine men will at some time in their lives receive psychiatric treatment".

(20)

Other aspects of National MIND's work have been concerned with consumers in a narrower sense, with the work of particular staff and Departments being involved with specific groups of consumers. Examples during the period of fieldwork included people dependent on minor tranquillizers, compulsorily detained patients, and discharged patients with inadequate opportunities for accommodation and employment (21). In September 1985,
the National Director wrote that during the following three years, MIND should work to achieve its objectives, including public education"...for all those labelled mentally ill, but especially those most severely crippled by mental illness." (22).

PROBLEMS WITH THE TERMS "CONSUMER"

Problems with the use of the term "consumer" have been described in Chapter 3 (23). Five respondents, all volunteers and former users of mental health services, had not heard of the term (24). Ten respondents referred to dislike of, or difficulties with the term, whilst only two spontaneously said they liked it. In the Local Associations Workshop on Consumer Involvement, it was concluded that "...the term "consumer" was generally disliked, but no alternative was agreed..." (25). In interviews, two respondents said they preferred the term "service user", whilst a Regional Director commented: We use "members" at local MIND groups and "clients" for statutory [services]". The term "consumer" was disliked because it was seen as jargon and because of its commercial connotations.

"...I think this play of words is a load of rubbish... calling a patient a consumer is unimportant, compared with how a service can be improved.. I'm sick and tired of discussions about "shall we call it this? Shall we call it that?"

(Interview. National MIND Staff Member)
"I don't like the term because it implies choice and competition... so I don't use."

(Interview. National MIND Staff Member)

"A middle class term. A lot of people I've worked with, if I'd said "you're a consumer" they wouldn't have related to the term".

(Interview. Regional Director)

Two people felt it was important to distinguish between people who were consumers at present, and those who had used mental health services in the past.

"The difficulty is... when [does someone] cease to be a consumer? It's labelling: "once mentally ill, always mentally ill". The mental illness of an individual is history, and no longer applies, so he is no longer a consumer"

(Interview. Council of Management Member)

In contrast, two respondents felt that the term "consumer" had advantages. A Regional Director felt that the term implied the encouragement of participation in decisions, and a volunteer commented:

"Well, I understand it's actually put a more polite social label on the patient... It might be a good thing because it might give a bit of status... to say you're a consumer, rather than a mental patient."

(Interview. National MIND volunteer)
As respondents gave a wide range of definitions of the term "consumer", it is not surprising that the concept of consumer involvement was beset with even greater uncertainty. Yet it was a term frequently used by National MIND staff in informal conversation. When asked their views on its meaning, respondents gave a wide range of answers (26). Eleven people, including seven volunteers, said they were unclear or uncertain what was meant by the term. A Regional Development Officer commented that MIND participants as a whole had doubts about this, and a few respondents referred to difficulties in defining the concept.

"..Oh God, you've got me there. Give me a lead. Oh you mean that..."

(Interview. Assistant Director).

"..I don't know what that means, quite. I've heard it used [within MIND] ..in a variety of contexts, some quite positive, some negative..."

(Interview. Council of Management Member)

Although respondents were encouraged to give definitions of consumer involvement, many of them found it easier to give examples. A majority of respondents referred to consumer involvement in MIND and/or statutory and other mental health services or organisations (Table 6.1) (27).
### TABLE 6.1.

<table>
<thead>
<tr>
<th>Areas of Consumer Involvement Referred to by Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=51</td>
</tr>
<tr>
<td><strong>A</strong> Within MIND</td>
</tr>
<tr>
<td>23</td>
</tr>
<tr>
<td><strong>B</strong> In statutory and other mental health services</td>
</tr>
<tr>
<td>14</td>
</tr>
<tr>
<td>General answer: Could apply to A and B</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>Other answer</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>Not able to answer</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

Tables 6.2 and 6.3 indicate main responses in relation to consumer involvement in MIND and in other mental health organisations and services. The wide range of responses suggests that consumer involvement meant different things to different people, or possibly, that different components of consumer involvement were uppermost in respondents' minds at the time (28).
<table>
<thead>
<tr>
<th>LEVEL</th>
<th>RESPONSE</th>
<th>NO OF RESPONDENTS MENTIONING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Government/Local services/Organisation</td>
<td>Running and planning services</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Consumer involvement in decision making</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Giving consumers a voice/interest in their experiences or perspectives</td>
<td>6</td>
</tr>
<tr>
<td>Central Government/Local Services/Organisational/Individual</td>
<td>Participatory or equal relationships with service providers</td>
<td>3</td>
</tr>
<tr>
<td>Individual</td>
<td>Service providers allowing consumers choice</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Service providers involving consumers in decisions concerning themselves</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Consumer involvement in a variety of levels</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Other responses</td>
<td>3</td>
</tr>
</tbody>
</table>
## TABLE 6.3

**ASPECTS OF CONSUMER INVOLVEMENT MENTIONED BY RESPONDENTS**

**WITH REFERENCE TO NATIONAL MIND**

<table>
<thead>
<tr>
<th>Level</th>
<th>Response</th>
<th>No of Respondents Mentioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer involvement in Policy Making</td>
<td>Consumer involvement in all levels of MIND</td>
<td>8</td>
</tr>
<tr>
<td>Consumer Involvement in the work of</td>
<td>Consumer influence on, or involvement in policy making</td>
<td>6</td>
</tr>
<tr>
<td>National MIND</td>
<td>Council of Management membership</td>
<td>2</td>
</tr>
<tr>
<td>Consumer influence on, or involvement</td>
<td>Involvement in Local Associations</td>
<td>4</td>
</tr>
<tr>
<td>in MIND's work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working as a staff member</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Working as a volunteer</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Specific Representation of Consumer</td>
<td>Representing the interests of consumers or their relatives</td>
<td>3</td>
</tr>
<tr>
<td>Interests</td>
<td>Consumer involvement in specific aspects of MIND work</td>
<td>8</td>
</tr>
<tr>
<td>Adding dimension to MIND on basis of</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Individual</td>
<td>Consumers making own decisions in casework with staff/concern for consumer</td>
<td>2</td>
</tr>
</tbody>
</table>

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In Chapter 3 it was concluded that consumer involvement is multi-dimensional, involving a variety of levels and degrees. Ten respondents gave definitions of consumer involvement in terms of a single example or a single level, whilst sixteen people indicated that they saw the concept as complex and involving two or more levels. A few respondents also referred to different degrees of consumer involvement, without themselves using the term. Some responses were difficult to classify according to level, because, for example, respondents gave their views on consumer involvement, or described it in general terms rather than referring to specific levels. The latter included: "a process of total participation in MIND", "responsibility in decision making" and "consumer involvement means the most important people.. are the people with problems with mental health and their experience is the most important on which to build a service."

Several respondents referred to specific examples of consumer involvement in National or local MIND (29). References to single levels of consumer involvement included:

"..Involving people in decisions about their own future and their present..."

(Interview. National MIND Staff Member)
"..We [members of the Legal Department] see ourselves as transferring power when we can to individuals. I say [to clients] let's get a policy together, and involve them in an ad hoc way."

(Interview. National MIND Legal Director)

These responses contrasted with more complex definitions which included more than one level of consumer involvement. Several respondents referred to consumer involvement in decision making in different levels of MIND and/or in mental health services in general. (See Tables 6.2 and 6.3. pp.128 and 129).

"..Consumer involvement means that people who have been mentally ill are involved in every level of the processes that run MIND: local, regional, national, and on Council of Management."

(Interview. Assistant Director)

"..Consumer involvement means the involvement of the person who receives the services.. it can go from views about it, eg, "I don’t want this medication" to management.. and making policies about the unit."

(Interview. National MIND Volunteer)
"..[Consumer involvement means] consumers being in decision making positions with respect to relevant organisations. the most extreme model I'm thinking of is the Arbours Association, where people are allowed to become psychotic, and yet help to run the place."

(Interview, Assistant Director)

An Assistant Director referred not only to levels, but degrees of consumer involvement:

"..Consumer involvement is a many-splendoured thing. anything from having residence in a hostel: eg, sitting on a spurious management committee. Consumer involvement can..be applied to just giving people the opportunity to moan, without necessarily providing them with the opportunity to resolve issues they are moaning about. I think most commonly consumer involvement is ..given by paternalistic [professionals].

"At the other end of the continuum I'd see involvement in a participatory relationship with all the experts..that would involve being given the opportunity to know what the options are in any given choice, opportunity to discuss priorities.. to have control over the way priorities are set, or the degree of control.. and then the way services are provided, and ultimately, I would see the consumer as being the ultimate arbiter."

(Interview. Assistant Director).
This respondent was unusual in his reference to degrees of consumer involvement, differentiating between paternalistic and participatory relationships with professionals, and contrasting "spurious" committee membership with "real power" at organisational level. Several other respondents referred to the problems of consumer involvement being tokenistic or paternalistic (30).

Four people included power sharing or changes in power in their definitions of consumer involvement (31).

"...Consumer involvement means an equal sharing of power... and giving a greater say to people with direct experience of mental health services..."

(Interview. Regional Development Officer)

"...I suppose [consumer involvement] links up with the philosophy of giving back power to [the patient]..."

(Interview. National MIND volunteer).

"COVERT" CONSUMER INVOLVEMENT

An attempt was made to assess the amount of consumer involvement in National and Regional MIND. This proved difficult for a number of reasons, including the problems of defining the meaning of "consumer" and of distinguishing between "consumers" and "non-consumers", with the inherent dangers of labelling and stigmatisation (32). Another
difficulty in estimating consumer involvement was that, according to several respondents, many MIND participants, whilst seeing themselves or their relatives as having experienced mental health problems, did not normally discuss this with other participants, or make it clear that their involvement was because of this experience.

For this reason, it was difficult to assess the amount of consumer involvement in the staffing of MIND or of Regional Advisory Committees or Council of Management (33), although estimating such participation in voluntary work in the National Office was relatively easy.

Respondents were not asked whether or not they, or their relatives, had experienced mental health problems, because this could have caused distress, and would have been an invasion of privacy, related to what, for some people, could have been a very personal matter. Had the research been on the British Diabetic Association, it would have been relatively easy to have asked participants if they had diabetes. This reflects, in part, the stigma and lack of social acceptability of mental illness, compared with some physical illnesses (34). Despite MIND's aims of public education, and its attempts to eradicate stigma (35), some respondents described negative attitudes of some MIND participants towards people with mental illness (36).

Other reasons for not asking respondents about their personal experience were based on an impression, from participant observation and interviews, of the nature of the organisation at National level, compared with the other voluntary organisations studied. MIND differed from most of the latter in that people's reasons for joining the organisation were usually
not explicit. This was partly because National MIND's aims, which were considerably wider than those of the other voluntary organisations studied, did not include self help and the sharing of common experiences (37). Council of Management members and staff appeared to participate because they wished to be involved in the running of MIND and its work, rather than to exchange personal experience or feelings as a group; and there were few structured opportunities for such sharing (38).

Twenty eight respondents were asked why they had originally become involved in the work of MIND (39). A wide range of reasons was given, with mental health problems being mentioned by three National and three Regional staff, but no Council of Management members. The mental illness of a relative was mentioned by another three respondents (40). Two staff members had published work about their experiences as consumers. Only one respondent said that his own consumer experience was a reason for being involved in MIND's work. In contrast, only one out of fifteen respondents in the other voluntary organisations studied was not involved because of her/his own or a relative's experience of mental illness or mental health services (41).

A few National MIND staff commented that it was difficult to know how many Council of Management and/or staff members had experienced mental health problems. One respondent commented: "...in Council of Management it is difficult to know what hat they wear..." meaning that participants with consumer experience might not be on the Council for that reason, but because they had been selected for particular skills, or as a representative of Local Associations or of a mental health profession.
Similar views were expressed in two Regions. One Regional Director indicated that about one third of his Regional Advisory Committee members had consumer experience, but added that such experience was "incidental. They are not there because they are consumers." However, in another Region "...two senior Social Services staff sought nomination because of their own consumer experience..." (42), and a third Region had a consumer representative on one of its committees, who was observed in a meeting to make his consumer experience explicit (43).

VOLUNTEERS

Working as a volunteer was the most "visible" form of consumer involvement in National MIND. Whilst consumer involvement as a member of staff, Council of Management or Regional Advisory Committee was often covert, volunteers were seen by many National MIND staff as constituting a distinct group of people with experience of mental health problems (44). All of the volunteers who were interviewed mentioned their consumer experience, usually in informal conversation.

I met nine volunteers in the National office during the period of fieldwork, seven of whom agreed to be interviewed. Two other people, who had previously been volunteers in National MIND, were also interviewed (45). Volunteers appeared to form two distinct groups. The first group comprised four middle-aged men who were members of a Local Association in London ("Dock Green" MIND) (46). Three people in this group were close friends. They shared similar experiences of several years in psychiatric hospitals, and had all attended statutory Day Centres, as well as the Centre run by their Local Association. Two members of this group said they had been volunteers in National MIND for ten and twelve years, respectively (47).
Two members of this group said they had been volunteers in National MIND for ten and twelve years, respectively.

One member of this group was not observed to come to the National office during the period of fieldwork. The other three volunteers did similar routine clerical work, mainly putting documents in envelopes, ready for posting. I sometimes joined in this task, with the agreement, or at the invitation, of the volunteers.

The other five volunteers worked, or in one case, had worked, in National MIND Departments. The volunteer who appeared to have had the most influence at Headquarters had taken on considerable responsibility and been involved in policy decisions of a Department. His work had included lecturing and writing articles, particularly for MIND's magazine. He said that he had come to see himself almost as a staff member.

Of the other respondents, two did secretarial work, and two were involved in the Library and Information Unit, using their work experiences and skills. Another volunteer worked in the Appeals Department (48).

Seven of the nine volunteers interviewed were asked if they had been involved in MIND in other ways (49). Only one of these respondents (the active participant in a National Department) had attended MIND meetings and conferences and two had had articles published in "Open MIND". None of the volunteers mentioned participation in the Council of Management or Policy Committee (50).
In Regional offices there was little involvement of volunteers. A few people with consumer experience did unpaid work in three of the established offices, and the Regional Director for MIND South East said that there were plans to involve consumers as volunteers when this office was established. Comments about volunteers included views that Local Associations offered more appropriate voluntary work, and that it was difficult for Regional staff to give enough time to meet volunteers' needs, given the demands of other work (51). The few volunteers in Regional offices included two patients from a local psychiatric Day Hospital who did secretarial and ancillary work, and a young man who visited one office to discuss his problems, who sometimes did minor electrical repairs (52). One Regional respondent said that his voluntary work was based largely on his own experience as a consumer, when he had felt devalued in hospital and had experienced accommodation difficulties. At the time of interview he was involved in research on DHSS Board and Lodging Regulations and, with a staff member, in training social work students.

THE INFLUENCE OF CONSUMERS ON THE WORK OF NATIONAL AND REGIONAL MIND

In Annual Reports between 1982 and 1986, MIND frequently claimed to represent consumers' needs and rights (53). The amount of consumer involvement in this representation was assessed by asking respondents:

"In - Department/-Region, to what extent do consumer views influence decision making about their needs and rights in the following ways?

(i) Staff consider consumers' expressed views and expressed needs."
(ii) Staff assess consumer views and opinions: a) informally, b) formally...

(iii) Consumers are actively involved in decision making" (54).

Eleven respondents from five Departments and the Campaigns Unit were asked part or all of this question (55). Several people felt there was variation in the extent that different Departments or staff members consulted consumer views, but seven respondents indicated that staff in their own Department considered consumers' expressed views and needs to a marked extent.

"...Very much so. Issues they raise are ones we feel we should take up..."

(Interview. Worker in Black and Ethnic Minority Mental Health Team (56) Community Development Department)

"...Enormous...Any policy I've brought up has had some consumer involvement in it. Consumers have initiated it, or I take into account consumer and other views..."

(Interview. National MIND Staff member in Legal Department).

Two respondents said that they did not often consider consumers' expressed views and needs because of their limited contact with them, but all Departments, except Appeals, had assessed consumer opinion. Only the Legal and
Policy and Information Departments did so formally. Most respondents said they sought consumer views in an ad hoc way, e.g., by informally asking consumers with whom they were in contact, their views of the services they received (57).

The Policy and Research Officer said that she assessed consumer views as part of her research, but added:

"..That is not how most of our policies are made. Policies are based on what we feel would benefit people."

(Interview. National MIND Policy and Research Officer).

CONSUMER INVOLVEMENT IN DEPARTMENTAL DECISION MAKING

According to respondents, there was little active consumer involvement in decision making in National MIND Departments. This was said not to occur at all in Policy and Information, Training and Education, and Appeals, and to occur to a limited extent in the Community Development and the Legal Departments. In the Community Development Department consumers had been involved in working groups, e.g., to examine the mental health needs of members of black and minority ethnic groups. A volunteer with consumer experience said that he had become involved in decision making in another Department. Such involvement appears to have been unusual, and was not mentioned by other volunteers interviewed.
CONSUMER VIEWS IN REGIONAL OFFICES

One respondent in each of the five established Regional offices, and the Regional Director of MIND South East, were asked about consumer involvement in Regional MIND work (58). Two of these respondents said that consumers' expressed views and needs were considered to a limited or fair extent; and this was felt to be "considerable" in three other Regions. Two respondents stressed the importance of maintaining personal contact with users of services. Staff members in two regions visited local psychiatric hospitals, including Special Hospitals, and the views of patients appeared to considerably inform their work. Until 1985, the Information Officer in one Region had given information and Advice on legal and other issues to patients in a Special Hospital. The Director of "Region C" provided a counselling services for consumers, whilst staff of another Region ran an Information Service, similar to National MIND's Advice Unit, which dealt with about 600 enquiries a year. The work of the Regional Development Officer and Community Development Workers, were said by the Regional Director to be influenced by the views and enquiries of consumers.

One Regional Director referred to the influence on his own work, and that of the Regional office, from contact with users of services:

"...I like to think views for the work of this office are based on ideas picked up from consumers...I have acute awareness of the problem of poverty from phone calls, letters, visits. A lot of it is pure observation. I was devastated to hear that one old lady had been 57 years in a mental hospital. Just seeing her brought it all home..."

(Interview. Regional Director)
Formal assessment of consumer views and opinions had been attempted by the staff of only one region (Region C), for whom it seemed to be a high priority. Such work appeared to be difficult because of the Regional Offices' limited resources, and one Regional Director indicated that this was the case in his Region. Both the Director and the Development Officer of Region C had undertaken research on the views and opinions of users of services in their Region, and the Director had written about his own experience as a consumer of mental health services and compiled a collection of consumer experiences.

Self Advocacy and Normalisation were important aspects of the work of Region C staff. The Regional Director established Self Advocacy schemes in wards in a psychiatric and a mental handicap hospital, and with the Regional Development Officer, made an assessment of the life of the wards and worked out, with ward participants, a programme to increase residents' choice, privacy and participation in decision making, and to lessen social distance between residents and staff (59).

The Regional Development Officer for C Region had run several Normalisation Workshops, and had publicised Normalisation methods, including an account of ways in which the principles outlined in "Common Concern" could be translated into practice, using Normalisation principles (60). Normalisation was less important in the work of other Regions (61), although in two of them there had been increased interest, with some staff attending courses on the topic. Overall, Advocacy played a more important part in Regions' work, and included the Advisory service for Special Hospital patients, and the enquiry service referred to above.
Of the National Departments studied, Appeals appeared to have the least consumer involvement in relation to consumers contacting the Department and staff assessments of their views and opinions. The Assistant Director of this Department said that no consumers had contacted him with views or suggestions concerning fund raising (62). At least one volunteer with consumer experience had worked in the Department, and a number of former consumers had unsuccessfully applied for fund raising posts (63).

The Assistant Director of Policy and Information said that staff in her Department were "...tuned into the consumer view, but how much depends on where they are placed in the Department." The two Advice and Information Workers were particularly in touch, as they answered phone queries and letters from consumers, as well as from other people, on a wide variety of mental health issues. As with the Legal Department, contact with consumers was initiated by consumers themselves. One Advice and Information Worker said that consumers' queries and problems sometimes influenced and informed the organisation's campaigns and its magazine, "Open MIND".

"...Campaigns...link in to us and ask about queries about minor tranquillisers, and we ask people to write into "OpenMIND" as well."

(Interview. Advice and Information Worker, National MIND).
The Campaigns Unit was set up in 1983 with an Assistant Director and an Administrator. In describing his own work, and that of the Unit, its Assistant Director emphasised consumer views and interests to a considerable extent.

"...I think the most important aspect [of my work is] to translate the concerns, views and experiences of consumers of services into an effective dialogue with the provider of the service...to provide a lobby for consumers, and...to demystify the services and treatments, and give consumers information on those to promote their capacity to give informed...consent to treatment and policies..."

(Interview. Assistant Director, Campaigns Unit)

Until late 1985, the most important aspects of the work of the Campaigns Unit concerned minor, and later, major, tranquillizers. According to the Assistant Director, MIND’s concern about minor tranquillizers went back to at least 1980, when staff received an increased number of calls for help with dependency on these drugs. The campaign on this issue owed its inspiration to these consumer enquiries, and began with the production of a "first Special Report on Minor Tranquillizers". The Assistant Director enlisted the help of the media in highlighting the problem, and appeared on radio and television programmes.

A "That's Life" Special Feature on minor tranquillizers, which featured the experiences of people who had contacted MIND about their own dependency, generated much publicity, and the organisation was deluged with a considerably increased number of requests for help at local,
regional and national levels. The "That's Life" programme was followed by a BBC publication offering advice, which was co-authored by the Assistant Director (64) and the start of a considerable number of Self Help Groups by Local Associations and other organisations. All this, the Assistant Director stated, was "directly related to the campaign."

"...It would be very difficult to claim that we took the consumer view before publishing [the first MIND report on minor tranquillizers], but we did address the sort of questions consumers had been asking us. The style reflects an attempt to argue their corner. We've tried to avoid being paternalistic: ie, telling people what's good for them.

..The "That's Life" survey was a way of involving consumers in the campaign, in that we didn't try to shape their views."

(Interview. Assistant Director, Campaigns Unit.)

As a result of the increased volume of enquiries on minor tranquillizers dependence, leaflets on this topic were produced, providing answers to some of the questions which consumers asked Advice Workers. Copies of first drafts were sent to twenty people, who had been dependent on minor tranquillizers, for their comments, which were then incorporated into later issues. The limited number of staff, and "very tight budgeting" has precluded wider consultation of consumer views (65).
Whilst the Campaign Unit's work was concerned with consumer felt and expressed needs, much of the work of the Training and Education Department aimed to meet the educational needs of statutory mental health professionals. Many of the Conferences, Courses and Workshops facilitated by the Department's Organising Tutors were influenced by the consumer perspectives, sometimes with speakers outlining their experiences as consumers. Tutors made efforts to "keep in touch with consumers" (66), and to discover what they thought of specific services which were the subject of the particular training event. One Organising Tutor said (67):

"...[They] make course participants sit up and think: "Yes, consumers have rights and status". It's a shock for [professionals] to see and hear...consumers hold the floor...as speakers."

(Interview. Organising Tutor, National MIND).

The Training and Education Department facilitated consumer involvement in MIND's Annual Conferences in 1984 and 1985. A leaflet for the 1985 Annual Conference "From Patients to People." stated:

"For many people, going into hospital or using community mental health services brings a change in status. People become "patients" or "clients", surrendering control of decisions and determination of their daily way of life...decisions may be taken without real consultation. When they are "patients", people may lose control over the most basic areas of their lives."
"...Can those who use and those who run mental health services ever become equal partners?" (68).

The 1985 Annual Conference was advertised as being of interest to "...people who are or have been users of mental health services..." (69), in addition to other people. The Conference considered ways in which traditional services had failed to involve consumers in decisions affecting their lives, and in the services they received, and examined examples of consumer involvement in the running of mental health services. Consumer involvement in the Conference was facilitated by offering free places to people who were unwaged, and many of the speakers and facilitators of plenary sessions were consumers who described their experiences (70).

**AN INCREASE IN CONSUMER INVOLVEMENT?**

During the period of fieldwork, Council of Management, National MIND staff and some regional and local participants considered proposals to facilitate and increase consumer involvement in the organisation. The next part of this chapter considers respondents' views on the extent to which consumer involvement increased between 1980 and 1985; and examines two proposals for increasing consumer involvement which were debated within National MIND in 1985.

Eighteen respondents (71) were asked how much importance was attached to consumer involvement in National MIND, compared with either five years previously, or in the case of relative newcomers, with the time when they had joined MIND. Of the sixteen respondents who felt able to make such an
assessment, thirteen felt that there was more consumer involvement in 1985, whilst three were unsure. Six respondents indicated that there had been a marked increase, making comments such as: "has developed considerably", "quite a bit more", "much more". The National Director said that there was:

..more [consumer involvement] than when I started [nearly two years before the interview]. It has developed considerably. Consumer involvement was something people paid lip service to. Relatively little was said to me, when I came, about consumer involvement. Consumer involvement developed over the last two years, particularly:

partly on the basis of Common Concern..."

(Interview. National Director, MIND)

Four people commented that organisational changes had contributed to the increased importance attached to consumer involvement. Three of these respondents referred to a Staff Policy Conference held in April 1984, at which there was a discussion about priorities for the organisation, and suggested changes in structure, including ways of increasing consumer involvement.

"...I think it's increasing because... five years ago [a Consumer Advisory Panel] (72) wouldn't have got off the ground..."

(Interview. Staff member, National MIND).

Most respondents who reported an increase in consumer involvement did so without qualifying their answers in response to this question. An exception to this was one National MIND staff member, who said:
"...Well, it is more important in subtle ways. I think some staff appointments over the past two years have been more sensitive, and have included ex-consumers, or people closer to the ground [with more idea] what it feels like to be a consumer. I think conscious effort on the part of some people, including the Director, to promote consumer involvement and take it on board - but patchy and ad hoc. Some Departments wouldn't touch consumers with a barge pole."

(Interview. Staff member, National MIND).

Four people referred to an increase in discussion about consumer involvement, but one respondent added:

"...It's on the agenda, which it was not two years ago. Not sure whether this reflects [its being] more important or not."

(Interview. Staff member, National MIND).

Finally, the chairperson of Council of Management felt that consumer involvement had increased in the organisation, compared with the years previously, because members of staff and Council of Management members were, overall, younger people with "a greater sense of awareness" (73). Another member, and former chairperson, of Council of Management, summed up her impressions of consumer involvement in MIND in the following words.


(Interview. Council of Management member).
In late 1984 the National Director wrote:

"..One important outcome of [structural] changes will be the involvement of more consumers or ex-patient representatives within MIND. At present, there is little direct involvement of consumers of mental health services in the decision making and policy structure of the organisation." (74).

In September 1985, the National Director wrote a draft paper, "MIND Strategy 1985 to 1988" (75) for discussion by Council of Management, Policy Committee and Regional Councils, which contained work priorities, objectives and goals for this period (76). The five objectives included attempts to:

"..revalue people who have been devalued by their experience of mental illness, the treatments they have received or the settings in which they have received that treatment..

"..encourage all services and social systems to help individuals.. to rebuild their citizenship following mental illness, and to develop the greatest autonomy and fulfilment.."

(77).

Two proposals were debated within National MIND in 1985. The first, which recommended changes in structure and accountability in MIND, aimed to make the organisation more democratic, and to increase involvement in decision making of not only consumers, but all Local Association participants and members of black and minority ethnic communities (78). There was concern to better represent the interests and views of the
latter, and to consider the needs of women and of ethnic minority groups when formulating work policies (79). A second proposal to increase consumer involvement concerned the establishment of a Consumer Advisory Network to advise MIND on various aspects of its policy (80). Other ideas to achieve consumer involvement in National MIND were discussed during the period of fieldwork, but few attempts were made to implement them, unlike the proposals outlined above (81).

During the eighties, MIND became a more complex organisation. Whilst the number of National Departments had remained steady over the years (82), the volume and scope of many Departments appeared to increase (83). The nineteen eighties saw further growth in the number of Local Associations and in regionalisation (84).

Soon after taking up post, the National Director concluded that this increasing complexity had resulted in failures in communication, and differences in perspective, about what MIND's aims should be. He commented favourably on growth in the organisation, but added:

"...There is a feeling of fragmentation throughout MIND. Many Local Associations feel that they are excluded from discussion and decision making at National and Regional levels, that their contribution is not valued. National MIND and Regional Offices often feel that Local Associations do not understand the issues or support their work." (85).
In an attempt to resolve these perceived difficulties, the National Director suggested "...proposals... for more democratic decision making and better accountability and communication within MIND" (86). These were sent for comment to local and Regional participants, members of Council of Management and National MIND staff. After considerable debate and some modification, the proposals were finally accepted at MIND's Annual General Meeting in November, 1985, with a decision to fully implement them by May, 1986 (87). The proposed new structure aimed to ensure better representation of Local Associations on Council of Management and on Regional Councils (88). The National Director indicated that he felt that it would also increase the participation of consumers and of members of black and minority ethnic communities in decision making in the organisation (89).

Increased interest in the latter appears to date from 1981 to 1982, when studies were made of services for people of Asian and Afro-Caribbean origin, and of their mental health (90). By the early eighties, a few Local Associations in London forged links with ethnic minorities, but such initiatives were unusual. Concern was expressed both by some National and Regional staff, and by some Local Association members about:

"... the lack of ethnic minority representation in MIND's committees at all levels, and would urge Local Associations, MIND Regional Councils and National MIND to look at how this situation might be remedied. It is hoped that all of MIND's Local Associations will look at their structures and services to ensure that they are not missing parts of their local community, and thus failing in their own objectives" (91).
Following this, a Working Party, with a membership from ethnic minorities, was set up to "explore the mental health needs of black and minority ethnic communities in the South East.. to run in tandem with a similar group in the West Midlands." (92). Data on inadequacies in services for these communities were collected by this Working Party. At the same time, the Legal Department found evidence of a disproportionately high number of black and Asian people being compulsorily admitted to psychiatric wards under Section 136 of the Mental Health Act (93). Problems faced by ethnic minority members in relation to mental health services were highlighted in several articles in "Open MIND" (94).

A Black and Ethnic Minority Mental Health Development Team was appointed in May 1985. Members of this team said, when interviewed, that their work included enabling Local Associations in the South East to make services accessible to black and minority ethnic groups; offering help with the setting up of projects at local level; initiating Racism Awareness Training for MIND staff; making representations to Central Government policy makers; and attempting to combat institutionalised racism in service provision (95).

The National Director initiated MIND's adoption of an Equal Opportunities Policy, making it clear that applications for jobs were welcomed from members of ethnic minorities and from people with experience of mental health problems and other disabilities, and from either gender(96). Five out of six Regional Staff who were asked about Equal Opportunities (97) said they were broadly in favour of employing people with consumer experience. One Regional Director commented that a staff member had been appointed specifically for this reason, and another Director commented in his Regional Office, "..most of the staff have personal experience themselves, or have families with mental ill health (98).
At the Annual General Meeting in November, 1985, the National Director suggested that Local Associations should adopt Declarations of Intent on Racism and on Disability (99), a proposal which was discussed further during 1986. In addition, a working party "Women in MIND" was set up in November, 1984 "to consider the needs of women with mental health problems" (100). Members of the working party expressed concern at the lack of appreciation of women's needs in male-dominated mental health services, and aimed to publish examples of good practice in services which met the needs of women (101).

A "CONSUMER ADVISORY NETWORK"

Concern to increase consumer involvement was voiced in a staff policy conference in April, 1984 and in MIND's Annual Conference in November of that year. Following this, the idea of a Consumer Advisory Panel (later called a Consumer Advisory Network) was mooted by MIND's Policy and Research Officer in December 1984. She initially proposed to the Policy Committee that this Network would "consider relevant policy matters and...make recommendations to the Policy Committee..." (102), in a similar way to the organisation's Professional Advisory Committee, which consisted of mental health professionals. Later, the Policy and Research Officer suggested that the Consumer Advisory Network should consist of "a core group of eight to ten members [and] a larger network of people who may be able to contribute on specific issues" (103). The proposals were debated by the Council of Management Policy Committee and Management Team. The issues which appear to have been most discussed included the aims of the Panel, concerns that it would be "tokenist", and the issue of whether or not staff and Council of Management members should "come out", and share with other participants whether or not they had themselves experienced mental health problems (104).
Consumer involvement in MIND was also debated by Local Associations in a workshop in May, 1985, with a proposal that Council of Management allocate places to people with consumer experience (105). The Policy and Research Officer drafted a letter inviting various people to become members of the Consumer Advisory Network and of its core panel, with a questionnaire asking them to state in what ways they would be available to help. She also estimated the cost of setting up and servicing the Network. After considering these documents, Council of Management agreed, at their meeting on 9th October, 1985, that a Consumer Advisory Network should be established, in line with the proposals of the Policy and Research Officer, and those of the National Director. The letters and questionnaire were then sent to Local Associations and other organisations and individuals.

FORMULATION OF POLICY PROPOSALS

Thus, "policy" proposals related to the structural changes, and to the setting up of the Consumer Advisory Network, were being formulated during the period of fieldwork. The implementation of the latter occurred, almost a year after the Policy and Research Officer's initial proposal, after the main period of fieldwork. Some of the proposals for structural changes, eg, the setting up of Regional Councils, were implemented during 1985, but most of them were not finally agreed until November that year, and were eventually implemented in 1986.
OBJECTIVES FOR CONSUMER INVOLVEMENT IN THE REGIONS

Information was collected from one respondent in each of the established Regions about the extent to which their Regional Office had clearly defined objectives in relation to consumer involvement (106). Only two respondents indicated that their Regions did have clear objectives. One Director said that his Region had objectives in the sense of:

"...a total blurring of lines. We get to the point that there is no necessity to differentiate between consumers and other participants." 

This respondent referred to two Local Associations where:

"...the beauty... is you have no idea if someone is talking from a background of five years on a psychiatric ward or no experience at all." 

(Interview. Regional Director).

One participant felt that objectives for consumer involvement would develop upwards in the organisation from the Local Associations, whilst another respondent referred to attempts to ensure that one-third of Local Association Executive Committee members had consumer experience. One Region had considered the co-option onto the new Regional Council of people with particular experience or skills, but:

"...We're not going out and finding consumers for the Regional Council. We wouldn't want people to be labelled consumers. Because we've ensured Local Associations have a good proportion of consumers [on Executive Committees],...we accept nominees have a better chance to be consumers." 

(Interview. Chairperson of a Regional Council).
The Director of Region C outlined various objectives related to consumer involvement, including proposals for a Regional Consumer Council, sending a questionnaire to Local Associations about the extent to which consumers participated in their Executive Committees, and the holding of a meeting for consumers convened by the new Regional Council. A number of respondents commented on the comparatively high extent of consumer involvement in Region C, and the Development Officer of this Region commented that such participation was "the fundamental baseline for every concern we have..it is the issue". However, the Director of this Region described the difficulties of operationalising his ideas:

"I don't know how to do it. We've talked about how to do it, and have circulated all Local Associations about the involvement [of consumers] in affairs.. I think many people [in Local Associations] genuinely.. don't understand.. If they did, they would be very shocked."

(Interview. Regional Director).

**CLEARLY DEFINED OBJECTIVES AT NATIONAL MIND?**

An impression was formed from participant observation that National MIND staff saw consumer involvement as being a "good thing", but that it was less clear how this should be achieved. This was borne out by responses to the question "Does MIND at National level have any clearly defined objectives in relation to consumer involvement?" (107).
Thirteen out of fifteen National staff replied "No." The only respondents to reply "Yes" were three Regional staff, one of whom commented that National MIND staff had a "...very strong commitment to learn about [consumer involvement]". The other two Regional respondents qualified their answers: "to some extent"; "I would question the seriousness of it."

Some respondents referred to the organisation's commitment to consumer involvement, but the lack of clarity about how it could be achieved:

"...I think it's fairly clear it must happen, but less clear ways of securing that..." (Interview. Staff Member, National MIND).

"...I think we're coming on ...we [are concerned] about consumer involvement... it gives us a warm feeling and we feel it would enrich and enhance the organisation..." (Interview. Assistant Director).

"...I think at National level there's an understanding - not a clearly defined objective, that we seek to increase consumer involvement in all levels of the organisation. I think people would see it as committed to [consumer involvement], but methods of achieving it are less clear..."

(IInterview. Assistant Director).

Views were expressed that the promotion or encouragement of consumer involvement had not gone much beyond the stage of discussion (108).
"...We're still thrashing in the dark on that issue. Everyone thinks consumer participation is a good idea...But when we say "In what way?", I suspect you'd get a million and one answers..."

"...We have meetings saying we should encourage [consumer involvement], but as far as the actual progress goes, I don't think it goes beyond talking...

(Interviews. Staff member, National MIND).

THE EXTENT OF CONSUMER INVOLVEMENT IN MIND

Finally, respondents were asked to assess aspects of consumer involvement in National MIND in relation to: Council of Management's and staff's consultation of consumer views; important decision making and taking on responsibility at National level; and consumers' influence on National MIND policy (109). Respondents were asked to rate each of these items on a five point scale: Nil (0) Slight (1), Fair (2), Marked (3) Very considerable (4); and as "not enough", "enough" or "too much". (110). Tables 6.4 to 6.8 show respondents' assessments (111). Each item received a low rating, overall, and the majority of respondents felt that there was insufficient consumer involvement/consumer consultation (112).
### TABLE 6.4

**EXTENT TO WHICH COUNCIL OF MANAGEMENT CONSULTS CONSUMER VIEWS**

<table>
<thead>
<tr>
<th>Rating</th>
<th>n21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very considerable</td>
<td>4</td>
</tr>
<tr>
<td>Marked</td>
<td>3</td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
</tr>
<tr>
<td>Slight</td>
<td>1</td>
</tr>
<tr>
<td>Nil</td>
<td>0</td>
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</tbody>
</table>

### TABLE 6.5

**EXTENT TO WHICH SENIOR STAFF CONSULT CONSUMER VIEWS**

<table>
<thead>
<tr>
<th>Rating</th>
<th>n31</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very considerable</td>
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</tr>
<tr>
<td>Marked</td>
<td>3</td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
</tr>
<tr>
<td>Slight</td>
<td>1</td>
</tr>
<tr>
<td>Nil</td>
<td>0</td>
</tr>
<tr>
<td>Varies</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Don't know</td>
<td>6</td>
</tr>
</tbody>
</table>
### TABLE 6.6

**EXTENT CONSUMERS INVOLVED IN IMPORTANT DECISION MAKING IN NATIONAL MIND**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very considerable</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Marked</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Slight</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Nil</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
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<td></td>
<td>1</td>
</tr>
<tr>
<td>Don't Know</td>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>
### Table 6.7

**Extent Consumers Involved in Responsibility in National Mind**

<table>
<thead>
<tr>
<th>Response</th>
<th>n32</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very considerable</td>
<td>4</td>
</tr>
<tr>
<td>Marked</td>
<td>3</td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
</tr>
<tr>
<td>Slight</td>
<td>1</td>
</tr>
<tr>
<td>Nil</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Don't know</td>
<td>3</td>
</tr>
</tbody>
</table>
### OVERALL INFLUENCE OF CONSUMERS ON NATIONAL MIND POLICY

<table>
<thead>
<tr>
<th>Level</th>
<th>Frequency</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very considerable</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Marked</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Fair</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Slight</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Nil</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Varies</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>

### AVERAGE RATINGS OF ASPECTS OF CONSUMER INVOLVEMENT IN NATIONAL MIND

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior staff's consultation of consumer views.</td>
<td>1.67</td>
</tr>
<tr>
<td>Overall influence of consumers on National MIND policy</td>
<td>1.54</td>
</tr>
<tr>
<td>Extent consumers involved in important decision making in National MIND</td>
<td>0.75</td>
</tr>
<tr>
<td>Council of Management's consultation of consumer views</td>
<td>0.62</td>
</tr>
<tr>
<td>Extent consumers involved in responsibility in National MIND</td>
<td>0.39</td>
</tr>
</tbody>
</table>
The vast majority of respondents scored each of the five rated items on consumer involvement as "nil" or "slight", and "not enough". Larger numbers of respondents rated staff consultation of consumer views, and consumers' influence on National MIND policy as "fair" or more, compared with Council of Management's consultation of consumer views, and consumer involvement in National MIND decision making and responsibility. The highest average rating (1.67) was given for staff's consultation of consumer views. About one third of respondents rated this "fair" or more, and there was a wider range of scores, compared with those given in answer to the other questions. In particular, only one respondent felt that Council of Management's consultation of consumer views was greater than "slight". Whilst five respondents thought that staff consulted consumer views "enough", only one gave such a response in relation to Council of Management. A few respondents commented that there was no structure to enable the council to consult consumers, although one member of this body said: "...the policies that Council of Management push emphasise the importance of consumers, if not their influence on particular policy points." (113). A few respondents differentiated between direct and indirect influence of consumer views on the staff's work and on National MIND policy. Active consumer involvement was generally described as limited, but indirect consumer influence was thought to be greater, in that staff were said to take consumer views into account.

"...By making visits and speaking to Local Associations, you get a feeling to some extent" so it gets translated and absorbed, and we hear from the Advice Workers what people are saying..."

(Interview. Staff member, National MIND)
Most respondents felt that the amount of consumer involvement in National MIND had increased, but that clear objectives for operationalising such participation had not yet been formulated. Unlike the other voluntary organisations studied, MIND participants’ experiences as consumers were not always made explicit, and only a minority of respondents said that they had become involved in the organisation because of their own experience of mental health problems. Some people with consumer experience were volunteers in National and Regional MIND. Despite the limited amount of active participation, it was argued that overall, consumers’ views and needs often influenced the work of Regional offices, and some National departments, to a considerable extent.

A wide range of views were given by respondents in relation to the meanings of "consumer" and "consumer involvement" in mental health organisations and services. Most respondents described "consumers" as users of particular services. As many as a fifth of respondents were uncertain or unclear about the meaning of "consumer involvement", although several people stated that it referred to participation, by (present or former) users of services, in decision making or responsibility within MIND or other organisations. Many Local Association participants, in earlier interviews, also indicated that they perceived consumer involvement to have this meaning, although most of these respondents were not specifically asked about this, – an omission which constitutes a weakness of the study.
In the rest of this thesis the term "consumer involvement" is used in a way which reflects both the views of respondents, given above, and the literature on participation, and is similar to the proposed definition of consumer participation in Chapter 3 of this thesis (11)):

Consumer involvement is the participation, of (present or former) users of services, in responsibility and/or decision making, which has an intended impact on services and/or policies which affect the individual participant and/or other service users.

In ensuing chapters of this thesis, "consumer involvement" refers to participation in this sense, particularly participation, in MIND or the other voluntary organisations studied, by people who have used mental health services, and/or who perceive themselves as having experienced mental health problems.

The analysis of consumer involvement within MIND, outlined in the rest of this thesis, includes consideration of involvement at any level of the organisation, from local to national; and in various degrees: from being given information to consultation, involvement in decision making and in specific responsibilities, and the running of a Local Association or the National Organisation (11). In addition, the analysis of consumer involvement in MIND includes consideration of participation facilitated both by people with consumer experience and by other participants.

The next chapter examines the nature and extent of consumer involvement in two Local Associations.
In Chapter 2 reference was made to the complexity of consumer participation and the variety of levels and degrees of such involvement. A detailed study of two Local Associations of MIND yielded material which indicates the nature and complexity of consumer involvement in these two voluntary organisations, and forms the subject of this chapter.

An initial attempt was made to assess consumer involvement locally by examining records on Local Associations in the Community Development Department in the National office, and by interviewing the Local Associations Coordinator (1). Pilot interviews were carried out to assess the nature and extent of consumer involvement in nine Local Associations in counties served by “Albion” Region (2). Information about each Local Association was collected by interviewing at least one of its main participants (e.g., Chairperson, Secretary or a paid worker), and/or a member of Albion Region staff who knew the Association well. In addition, the Regional Director and Regional Development Officer completed a brief questionnaire comparing Local Associations on a number of components of consumer involvement (3). Pilot interviews indicated that there was frequent, and sometimes quite considerable, consumer involvement in the running of projects, and in certain responsibilities...
such as fund raising, but comparatively little in the Executive Committees which ran the Local Associations. Only one Association was said to have more than one Executive Committee member with consumer experience.

From the initial sample of Local Associations, two were chosen for detailed comparative study. "Eastvale" MIND was selected because it had the highest amount of consumer involvement in the management of the Local Association, with five users of its day centre on its Executive Committee, although none of them was an officer of the Association (4). "Westhill" MIND was chosen because it was one of several Local Associations with no consumers, but several mental health professionals, on its Executive Committee (5). Following pilot interviews, officers of the Executive Committees and staff, and later, users of the Associations' projects, were approached to ask if they would agree to a study (6). Proposed methods of study were outlined, and it was stressed that information given would be treated in strict confidence, and that the researcher would like to be actively involved in the Local Association during the period of fieldwork. Two main methods were used. Participant observation was carried out, particularly in Eastvale MIND's day centre and in two social clubs associated with Westhill MIND. When participants and the researcher had got to know each other fairly well, in-depth and semi-structured interviews were conducted with day centre and club members, Executive Committee participants and other volunteers, staff employed by the Local Associations and local mental health professionals. The latter were asked about their views of the Local Association. In addition, records, such as Annual Reports and minutes of meetings, were examined (7).
Before describing Eastvale and Westhill MIND further, it should be stressed that the ensuing account merely describes the Local Associations during the period of fieldwork. An impression was gained that MIND was a dynamic, changing organisation at all levels. A return to the Local Associations, several months after initial fieldwork, revealed that they had both changed in several ways. If participants had been interviewed a few months later, their responses might have been very different (8).

Differences between the Local Associations

At the start of fieldwork, Eastvale and Westhill MIND differed in several respects which will be considered in turn. These differences included:-

a) their age as organisations;
b) consumer and professional involvement in their Executive Committees;
c) their complexity as organisations and their range of aims and projects.

Westhill MIND has its origins in a Local Association, founded in 1909, of the Central Association for Mental Welfare which was concerned with the education and welfare of people with learning disabilities. The Westhill Association was "...dormant during the War period and when it revived in 1946, it became affiliated to the National Association [for Mental Health].." (9), and became increasingly concerned with mental illness.
In the late sixties, Westhill MIND "...reached a crisis point as all existing Officers felt they could not continue to serve indefinitely and either the Association would have to be wound up or its future carefully examined..." (10). A constitution for a new Local Association was eventually drawn up, and the present Westhill MIND was inaugurated in 1969 and affiliated to the National Association the same year (11).

Westhill MIND has always had considerable involvement of local mental health professionals in its Executive Committee (12). During the sixties these included the Physician Superintendent of the local psychiatric hospital, who was nationally known for pioneering work in community care for people with mental illness, and in ensuing years the Local Association opened several group homes and a social club, and continued its work on public education on mental health issues (13).

Eastvale has also had two Local Associations. The first of these, started in the early seventies, soon folded and some respondents attributed its lack of success to professional dominance on its Executive Committee and a failure to involve consumers and laypeople (14). The present Eastvale MIND, which was inaugurated in 1979, was started by a residential social worker in "Poplars", a local mental health hostel and developed from the meetings of the "Friends of Poplars", in which residents of the hostal had been involved. Some writers have stated that the shift of power from the elite to the disadvantaged (eg, from professionals to consumers), is an important component of participation (15). The residential social worker and other mental health
professionals decided to effect this shift by involving service users and laypeople in the running of the Association. Once Eastvale MIND was established, the professionals withdrew, remaining co-opted Executive Committee members, and ensuring that they did not take a dominant part in running the Association (16).

During the period of fieldwork, all Westhill MIND's Executive Committee participants had a former or present professional occupation. The Chairperson was a consultant psychiatrist and of the other twelve officers and members (17), six were, or had been social workers, four of them specialising in mental health (18). Other participants included a former psychiatric nurse, a schoolteacher for children with learning disabilities, a senior Local Government officer, a school secretary, a solicitor, and a journalist who was also a local Councillor. No committee members said that they had had consumer experience.

In contrast, Eastvale MIND's Committee came from a wider range of backgrounds and the Steering Committee's aims to encourage the involvement of consumers and laypeople in running the Association seemed to have been achieved in terms of Executive Committee membership. Four participants, including three of the five day centre members on the committee, were unemployed (19). The chairperson was a residential social worker at "Poplars" but had entered this work from industry after becoming involved in MIND. Other participants included a retired industrial manager, a retired Gas Board official, a quantity surveyor and two students. A consultant psychiatrist, and a community liaison officer
and a mental health social worker (both working for local Social Services) were co-opted and non-voting members of the Association.

The two Local Associations differed in the range and complexity of their aims and projects. During fieldwork, the Director of Albion Region commented: "Eastvale MIND is the day centre, and the day centre is Eastvale MIND." Whilst the Executive Committee were concerned with other matters such as starting an accommodation project and a befriending scheme, much of participants' time and energy was observed to be expended in matters concerning the centre. Much of the Chairperson's Annual Report for the year ending 1984 concerns the day centre, although links with the statutory sector and public education are also stressed (20). The Annual Report for the following year describes new projects: self help groups, an accommodation project, provision of holiday accommodation and a home visiting service. Participants were far more involved in fund raising than was the case in Westhill MIND.

The Executive Committee and staff of Westhill MIND were concerned with a much wider range of projects: five group homes and a new hostel, a resource centre, including drop in and information facilities, a social club and educational activities. In addition, a Development Worker had been involved in setting up several neighbourhood support groups in or near Westhill (21).
Participants were asked what they saw as their Local Association's main aims (22). The vast majority of respondents, particularly those in Eastvale MIND, and all Executive Committee members, mentioned service provision (23). Public education, campaigning and influencing statutory services, and giving information or advice were mentioned by several Westhill Executive Committee members and staff. Few Eastvale MIND respondents mentioned aims other than service provision (24). (Table 7.1). Only one respondent in each Local Association specifically mentioned consumer involvement as an aim (25).
<table>
<thead>
<tr>
<th>Service Provision</th>
<th>Eastvale (n 29)</th>
<th>Westhill (n 23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Education</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Campaigning/influencing statutory services</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Information/advice</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Publicity</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
Several Westhill MIND club members (but no Eastvale day centre members) did not know the main aims of their Local Associations (26). Non-Executive Committee members of the day centre rarely mentioned aims of the Association which were not directly related to the day centre itself. Provision of a place to meet, and of social and recreational facilities, were often mentioned by these respondents.

In both Eastvale and Westhill, most (non MIND) professionals saw the Local Associations' main aim as constituting service provision. Whilst only one of the Eastvale professionals mentioned a service other than the day centre, several Westhill professionals referred to accommodation projects and/or other Community Services, although only one respondent mentioned the Association's Social Club. Several Westhill professionals commented on the Local Association's role in campaigning, public education, or the provision of information or advice. In contrast, only one Eastvale mental health worker mentioned aims other than service provision. Several professionals in Westhill, but only one in Eastvale, referred to the Local Association's close liaison with local statutory mental health services. Overall, neither Local Association was thought by professional respondents to have much influence on local statutory policies or services.
Differences in the Associations' range of projects and complexity was partly related to differences in statutory funding. From the late seventies, Hillshire Social Services made grants to Westhill MIND to provide services and to pay staff employed by the Association. In addition, the Social Services Department seconded one of its Social Workers to become a MIND County Development Officer. From Social Services funding, Westhill MIND set up a hostel in 1980, which closed a few years later. In 1983, the local District Health Authority provided funding for the running and staffing costs of the Resource Centre, and in June, 1985, the Local Association opened another hostel financed from joint funding. In contrast, Eastvale MIND had never received any money from Local Social Services or the District Health Authority. ("Not even the money for a Scrabble set", according to one respondent). However, in 1983, the District Health Authority provided a building for the day centre, with running costs and staff salaries paid by the Manpower Services Commission.

Westhill MIND, which became a Limited Company in 1986, handled a relatively large amount of money and its Executive Committee and subcommittee meetings were sometimes abstruse and concerned with complex matters related to building insurance and the Law, which involved specialised knowledge and expertise. Eastvale MIND's Executive Committee meetings were relatively easy to follow and mainly related to matters affecting the day centre (27).
The Steering Committee of Eastvale MIND had decided that a priority of the new Local Association would be the establishment of a social club for people with, or recovering from, mental illness. It was planned to eventually expand this into a day centre, as it was felt that there was a lack of such a facility in the town centre. In 1982, the day centre eventually started in a Community Centre with Manpower Services Commission Funding for a Manager, and in December, 1983, it transferred to premises belonging to the local District Health Authority near Eastvale's town centre.

"... The atmosphere seemed relaxed, not dynamic: a few men playing pool, the rest of us chatting quietly. It seemed a place where people could drop in..." is an early impression from participant observation notes (28). The Centre was open seven days a week, including Bank Holidays, usually from 10 am to 9 pm. On most days, a steady stream of people called at different times, particularly members of the centre and of the Executive Committee, and visitors at weekly Bingo sessions. Downstairs in the main room people sat in chairs lining the walls, and smoked and chatted, sometimes over snacks and cups of tea and coffee. Some members played pool or Scrabble or used the computer for educational purposes or for games. Upstairs was a small kitchen, the staff office, and a Quiet Room used for committee meetings, games and occasional sessions in yoga and craftwork. On some days, fifty or more people visited the centre, and the building seemed cramped, with few spaces for people to chat privately.
Westhill MIND's Resource Centre occupied the first floor and basement of a large terraced house near the town centre. It opened in Spring, 1984, and provided drop in facilities, counselling, information and advice. Up to twenty people attended Zeta Club on Tuesday evenings and an associated lunch club which met on Fridays, but at other times during the period of field work the Centre often had few callers (29). Zeta Club had changed in its aims and intended membership. It was set up in 1973 by a mental health social worker for social rehabilitation of people who were being discharged from hospital (30), but by 1984 it was designated a neighbourhood support group with its membership open to anyone living locally.

Westhill MIND's first Development Worker, in conjunction with statutory mental health workers, set up five other neighbourhood support groups to combat loneliness and depression, and as a component of community mental health services, which were being developed in the town. Both Eastvale MIND's day centre and Zeta Club had been set up specifically for people with a diagnosis of mental illness. Eg, the Chairperson of Eastvale MIND stated that, through its day centre, ".. MIND is to some extent satisfying a need in the field of community care for the mentally ill..". In contrast, it was intended that neighbourhood support groups should be used by anyone living nearby, and enable people who had used mental health services to integrate with other members of the community rather than being set apart as a distinct and separate category of people with markedly different needs to others. Once the Groups were established, the Development Worker withdrew, leaving their running to
others, but making himself available for advice if necessary (31).

Zeta Club, and Delta Club, another neighbourhood support group, were chosen for study. Delta Club met in a room in the basement of a huge tower block in a large council housing estate on the outskirts of the town.

THE NATURE OF "VOLUNTEERING"

In both Local Associations a considerable amount of voluntary work was undertaken, both by people with personal experience of mental health problems, and by other members. However, participants referred to only some of these people as "volunteers". Executive Committee members, although giving their time voluntarily (32), were not so described. Users of Eastvale MIND's day centre did most of the voluntary work in the centre, but were called "members" by all participants. In Eastvale MIND the term "volunteer" was used to refer to people who were seen as being involved because of their wish to do voluntary work (other than serve on the Executive Committee) without becoming a day centre user. During fieldwork there appeared to be only five volunteers in this sense. One respondent said that volunteers were often quickly elected onto the Executive Committee. Although a majority of day centre members did some sort of voluntary work in the centre, some respondents said that it was difficult to get volunteers, and the Manager appeared on local television in an appeal for more volunteers for the Local Association. In retrospect, it appears that some participants felt that consumer involvement was insufficient for the work of Eastvale
MIND or the needs of day centre members (33). Cook suggests that participation may increase in times of scarce resources (34), and it seems likely that if the Local Association had recruited more ("non-consumer") volunteers, the amount of consumer involvement in some tasks would have decreased.

In contrast, Westhill MIND had a large number of participants who joined the Local Association as volunteers and were not Executive Committee members. During fieldwork there were about thirty active volunteers, many of whom were students or graduates of the town's University with which Westhill MIND's Development Workers had links (35). Both Local Associations ran courses for volunteers, with or without consumer experience, in conjunction with local statutory mental health professionals (36).

**DIFFERENCES IN CONSUMER INVOLVEMENT**

A number of differences in consumer involvement was observed in the Local Associations. These related to: a) differences in role visibility and overlapping of roles; b) the extent that individuals had formal responsibilities and accountability to Executive Committee and staff.

In the Clubs, particularly Zeta, consumer involvement was mainly informal, with anyone who wished spontaneously participating in particular tasks. Some consumer involvement in the day centre was
also informal in this sense, but much of it was characterised by what I shall refer to as high "Role Visibility": i.e. involving clear cut roles, tasks and responsibilities. In Delta and Zeta Clubs there was little distinction between "members" and "volunteers", but in the day centre people occupied quite discrete roles which were clear to participants other than newcomers (37). These roles included "day centre member", "day centre member doing steward duties", "volunteer" and "visitor".

From the time the day centre was established, stewards, many of them day centre members, undertook voluntary duties. Throughout the time that the centre was open, a Steward was responsible for several tasks, including: welcoming visitors; ensuring that everyone who entered the centre signed a book (38); dealing with telephone queries; making beverages and snacks, as requested; collecting the money received from this; washing up. Some Stewards offered informal counselling and support to members, and occasionally to people who visited the centre. Certain Stewards were observed to act as arbiters in disputes and/or to advise members when rules, mostly concerning the use of the billiard table, were not being followed. Stewards also occasionally dealt with what was seen as disturbing or disruptive behaviour. In addition, they let the Manager know when members or visitors wished to see her, and told the former when she would be available. Stewards had responsibility for the day centre in the absence of the Manager and other staff. Some people volunteered for Steward duties, whilst others were asked by Pam, the day centre Manager, to undertake this role. Interview responses suggested
that few, if any, contenders were turned down by Pam, but a few respondents indicated that her predecessor had chosen members as Stewards, not primarily because of their wish to participate, but because of his perception of their ability to do the job well.

Each week Pam drew up a duty rota, allotting each Steward one or two duties, usually of four hours, at times convenient to her or him. The rota was pinned on the day centre noticeboard in a position where everyone could see it, representing, it is suggested, the high role visibility of this type of participation.

A visitor to the day centre could usually see clearly who was "in charge", as the Steward when not otherwise engaged, sat in a chair designated "the Steward's chair", which faced the door leading into the centre's main room. In contrast during his first evening with Zeta Club, the researcher was struck by the fact that he did not know "who was who". There was little distinction between people who called themselves "volunteers" and other participants. A Development Worker, and two people who took on much of the responsibility for the club, mingled in with other people, indistinguishable from anyone else. There was no sense of anyone being in charge or performing a distinct "volunteering" role. The atmosphere was reminiscent of Clark's description of a therapeutic community in a psychiatric hospital:
"...There are people about, but there is no way of telling who or what they are..

"The visitor will gradually sort the people out identifying [staff and] patients, though he will see that the barriers between the roles are slight and that leadership may pass to anyone in the group at any time." (39).

In their setting up of Delta Club, the Westhill MIND Development Worker and a statutory social worker had hoped to achieve a similar non-hierarchial structure, where decisions would be made democratically, uninfluenced by themselves, with all members playing an equal part in the running of the Club. Whilst an early impression was formed that, like Zeta Club, it was difficult to distinguish members from non members, Delta Club had a very definite leader, May, who appeared to the researcher and to some respondents to play a very dominant role in decision making. Many members seemed to accept this, and looked to May to make decisions about activities. Whilst many events were spontaneous and unplanned, May was usually busy organising and deciding what would happen. The social worker involved in the Club sometimes also provided leadership in a less direct way.

The comparatively high degree of role visibility, and the clear differentiation between centre members and other participants, made the extent and nature of consumer involvement relatively easy to assess in Eastvale MIND. Executive Committee officers, and visitors, such as players at the weekly Bingo sessions, came to the Centre, but they did not seem to become integrated as full members. In the Clubs, it was observed that people could less easily be divided into those with
personal experience of mental health problems who were "members", and people who were not "members", but present in some other role such as "volunteer" or "Bingo player". This appeared to be for two reasons. Firstly, the day centre was open 365 days a year, whereas Delta and Zeta clubs met once and twice a week, respectively (40). Secondly, many participants in the Clubs, particularly Zeta, appeared keener to avoid making distinctions between different participants and were conscious of the resultant problems from doing so (41). However, it should be stressed that the relationship between day centre members and other participants usually appeared to be informal, relaxed and friendly, and was probably little different in this respect to club members' relationships.

Nine Zeta members were asked how they saw their role in the Club (42). Five said they saw themselves as both club member and volunteer, three felt they were members, including one who attended a volunteers' group, and one said he was neither member nor volunteer. No respondent saw herself or himself as a volunteer only.

"...Both, I think. Neither is more important than the other. I went along as a volunteer, but I got a lot from it."

"...I went as a client to begin with, but then got better quickly...other volunteers needed someone with dedication who could be here all the time, so I became a volunteer."
Mainly as a member, because I find myself slipping into the role of client, and forget I'm a volunteer.

(Interviews. Zeta Club participants, Westhill MIND)

For a few respondents, the categories of "member" and "volunteer" had limited meaning:

"I hadn't really thought of it in that way... The main aspect of going is social contact. I benefit from it, and give it, so very difficult [to say whether I am a "member" or a "volunteer".]

"Well, I don't think of myself as a volunteer, but describe myself as such to others. If a friend asked me. I always qualify it, though..."

(Interviews. Zeta Club participants, Westhill MIND)

Despite the lack of clear differentiation between members and volunteers, and the blurring of roles in Zeta Club, five out of ten respondents felt that there was a distinction between the two groups (43). Two participants said that their own consumer experience made it less likely that people would talk to them about problems (44).
"...I think there is a difference... I feel stuck in the middle because people don't confide in patients. They'd rather talk to a volunteer because they see them as someone without problems... but there's less distinction, and [members and volunteers] tend to blend together..."

(Interview. Zeta Club participant, Westhill MIND).

In Delta Club "member" and "volunteer" were terms which did not present difficulties of meaning to respondents. Two people saw themselves as members, three as volunteers, two as both member and volunteer, and one as neither. One respondent commented "we are all members".

Some Zeta Club respondents said they welcomed the lack of clear distinction between members and volunteers, but this was said to cause discomfort to some would-be volunteers who saw their role in terms of "doing things for people" (45).

The rest of the Chapter considers the nature and types of responsibility and involvement in decision making of day centre and club members.

In Eastvale MIND, most day centre members were involved in some sort of responsibility in the centre. Two samples were chosen for interview: members with a clear role, such as Steward or Executive Committee or subcommittee member, and those without such a role.
However, it was found that all but three respondents had been involved in some sort of responsibility in the Local Association (46). Various ethical problems were encountered in interviewing respondents selected through stratified random sampling (47), and to avoid these difficulties, Westhill club members were approached only when sufficient rapport was established, and it was reasonably certain that they would enjoy being interviewed (48).

At the time of fieldwork no club members had occupied formal positions of responsibility in their Local Association (49). In contrast, five Eastvale MIND day centre members served on the Executive Committee during the period of fieldwork; and in addition, several other day centre members had been nominated for positions on the Executive Committee in previous years, and/or were present or former members of subcommittees concerned with fund raising or the day centre's computer.

Whilst many day centre tasks, such as preparing refreshments and washing up, were performed by the Steward on duty, many jobs were not assigned but were undertaken by anyone who felt like helping: eg, moving furniture before the weekly Bingo sessions, checking cards for a "full house", and making refreshments for the visitors. In the clubs tasks were rarely designated by other people. Whilst the Steward was often the only day centre member to have a key to the kitchen, in the clubs anyone could decide to make tea or wash up. In both Local Associations some members took on particular responsibilities such as locking the centre at night. Two Zeta Club members did much of the cooking for the Friday lunch club, and in Eastvale MIND one member acted as general handyman, and another procured and drove a minibus for a day's outing.
In the day centre decisions were made in a relatively formal way: in three subcommittees for the day centre itself, and for the computer and fund raising, and in monthly open meetings which were started shortly before the period of fieldwork. The former appeared to be only for subcommittee members, but open meetings were for all day centre members, and were also attended by Officers and some members of the Executive Committee. Day Centre members' suggestions and requests were considered, and some decisions made e.g., about social events and trips out. Certain issues were discussed further by the Executive Committee (50), and between the Manager and particular Day Centre members.

In contrast, a number of Zeta Club members commented that the club was informal and "just happened", with limited scope for making decisions or for formalised responsibilities:

"..I've never been present when an important decision has been made."

"..There haven't really been any important decisions .. It seems to roll on without any major decisions being made..".

(Interviews. Zeta Club participants, Westhill MIND).

The attempt of a former member to make things more formal, e.g., by holding discussion meetings, had been firmly rejected "..If it was more formal, people wouldn't come here.." remarked one participant. Several people said they welcomed the informality, but a few felt that some
members did not participate sufficiently and relied on others to make decisions (51). Most respondents saw certain people as being most involved in responsibilities and decisions related to running the club. Four members were seen as particularly involved, especially two people who said their active participation was because of their own consumer experience (52). These participants were usually responsible for cooking Friday lunch and for locking and unlocking the Centre. The Resource Centre Worker was responsible for finances, but staff members, who sometimes attended Club meetings, were not seen as playing a major role in its running.

The degree of formality of decision making and responsibility was related to accountability. The accountability of club members was limited. Delta Club had no accountability to Westhill MIND, whilst in Zeta Club the only accountability (to the Resource Centre Worker, in the first instance) concerned the rooms and crockery used, and the locking of the centre after use. This accountability was not observed to be formally spelt out. Stewards in Eastvale MIND had far more accountability. They were responsible for the centre in the Manager's absence, and other members were normally expected to abide by Stewards' decisions. In a Stewards meeting there was a discussion about what they should do if members were disruptive or broke rules. Pam, the Manager, and Len, the Secretary of the Executive Committee, told the Stewards that their decision was binding on such matters, and that, in event of a disagreement, they should refer the matter to Pam. This meeting
also included some detailed instructions from Len concerning the use of a new microwave oven. Stewards were told that they were responsible for its safe use, and were to allow other members to use it only after they had received appropriate instruction. A long and detailed list of typed instructions concerning the microwave was later compiled. Stewards' holding of the keys and specific responsibilities have already been referred to (53). But their accountability and their difference in role from other members should not be overstressed. Although their duties were partly determined by the Executive Committee, Officers and Managers, they were allowed considerable discretion in the way they carried out their responsibility. Most Stewards interacted informally with other participants, playing games and conversing with them, and the majority came to the centre outside their spans of duty. The role style of the majority of Stewards was democratic, although some respondents felt that a few of them were inappropriately authoritarian at times (54).

SPECIFIC TASKS AND RESPONSIBILITIES

Day centre and club members were involved in a number of specific tasks and responsibilities, which included counselling, fund raising and educational and publicity activities.

In both the day centre and Zeta Club, members were observed at times to give each other considerable help and support. Some Stewards had attended a counselling course and, as part of their
duties, counselled distressed people who visited the centre. One member, Eve, had expended considerable energy in setting up and running a telephone network service, and later a self help group, which met outside the centre for people who, like herself, suffered from depression (55). The giving of support and help to other members was stressed by some respondents:

"..A staff member asked me to see this lad that was going to kill himself. I .. asked him to come back to the centre which he did .. for two months."

(Interview. Day Centre Member, Eastvale MIND)

"..I tried to help Ros one day .. when she was very depressed. I talked to a young fellow who drank too much; told him not to drink, find other interests, boosted his confidence .. I've spoken to ladies - sort of shared experiences. I've told them about books I've read which I have found helpful."

(Interview. Zeta Club member, Westhill MIND).

Both centre and clubs had a number of members who met each other frequently and knew each other well (56).

"..a lot of us seem to be closely knit. I know quite a lot of members from hospital days before I or they came here, and I think it's important that we help each other outside the system."

(Interview. Zeta Club member, Westhill MIND).
No Zeta Club members had been involved in fund raising, although two people said they would like to participate in this activity. There was far more consumer involvement in fund raising in Eastvale MIND (and far more fund raising, probably because of the lack of statutory funding). Nearly half the day centre respondents had helped with fund raising for the Local Association at some time. Events for this were observed to be organised and run mainly by day centre members, although the Local Association's Secretary took ultimate responsibility for this activity, and sometimes vetoed decisions of the Fund Raising Committee, according to its Chairperson. A meeting of this subcommittee was observed to be lively, with many suggestions for fund raising, an area which did not appear to be discussed in Westhill MIND.

In both Local Associations, most members' involvement was limited to the centre or club (with the exception of fund raising in Eastvale MIND). This was particularly true of Delta Club, whose links with Westhill MIND were, in any case, tenuous. Only two Delta respondents had visited Westhill MIND and some had not heard of the Local Association (57). In contrast, the majority of Zeta Club respondents said they had been involved in the Local Association, besides being a club member (58), eg. attending support meetings and/or a recent course for volunteers. Three people had attended the Local Association Annual General Meeting, compared with over twenty day centre members at Eastvale's Annual General Meeting (59), and another two participants had attended one or more Executive Committee meetings. In Eastvale MIND these meetings were not normally open to day centre members who were not on the Committee.
Some day centre and club members were asked to what extent they were involved in publicising their Local Association, relevant campaigning, advocating the needs of members with mental health problems, and educating the public, and student and trained professionals (60).

The centre and clubs were sometimes visited by students of psychiatric nursing, social work and social sciences (61), and members were thus sometimes indirectly involved in their education. Two Zeta Club participants, but no Day Centre members, had publicised the Local Association and provided public education, one through her involvement in an information stall about MIND and mental health; the other through organising the Resource Centre's small library, which was open to the public, writing leaflets about mental health and screenprinting a poster. This participant had also visited a Group Home and done administrative duties in the Resource Centre. Another club member had done clerical work and typing for the Local Association.

There seemed to be few respondents who had been involved in advocating the needs or rights of members. Exceptions were Eve, who had spoken to the local media about the needs of people with depression in Eastvale, and Liz, who said some Zeta Club members had acted as advocates.

"...quite a few times...people who've been ill, we have come round to their houses and have taken them up to hospital. If people are ripped off by landlords, we have pointed out the Law and their rights, and have tried to do something for them."

(Interview. Zeta Club member, Westhill MIND).

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During fieldwork, no members in either Local Association were involved in campaigning, but shortly after this, Westhill MIND started a Campaign Subgroup and a Patient Advocacy Group, in both of which consumers were considerably involved. These developments arose out of the wish of some participants to increase consumer involvement.

**INCREASING CONSUMER INVOLVEMENT IN WESTHILL MIND**

For at least a year before the start of fieldwork in Westhill (62), participants had been concerned about what they saw as an excess of professional involvement and a lack of consumer involvement (63). This concern had been shared by members of the Executive Committee, staff and some Zeta Club members, and was debated on a number of occasions. In the words of the Chairperson:

"...the 1984 Annual General Meeting in June, 1984 saw criticism of the Executive for being professionally biased and dominated. This criticism was repeated when the Local Association's first Development Worker left, and April, 1985 saw an open meeting to discuss where Westhill MIND should be going and who should be leading it..." (64).

Reasons for a wish to increase consumer involvement included beliefs in the value of the views of consumers, and a feeling that their opinions and needs would be better represented if they were more involved, and professionals were less involved, in the Association.
This reflected increased concerns (described in Chapter 3) to more effectively represent consumer views in Health and Social Services (66); and to decrease professional power and give greater credence to consumer opinion (67).

The Executive Committee attempted to increase consumer involvement by opening some of its meetings to club members to hear their views (68) and by deciding that changes should be made at the 1985 Annual General Meeting of the Association to ensure increased participation of consumers and laypeople on the Executive Committee. Nominations for election to the Committee were invited from Zeta Club participants and from volunteers who did not attend the club. At the Annual General Meeting in June, 1985, the lay secretary and treasurer were re-elected, as were six of the seven mental health professionals. In addition, a part time staff member (seconded by Social Services), and five non-mental health professionals, including three Zeta Club members, were elected. After this Annual General Meeting, the Development Worker commented that the Executive Committee contained some consumers, and she hoped that consumer involvement at this level would be increased. By 1987, according to another staff member, the majority of committee members had had experience as consumers of mental health services (69).
Several Westhill respondents expressed dissatisfaction with what they saw as an excess of professional involvement and a lack of consumer involvement in their Executive Committee. A number indicated agreement with the Committee's proposals to increase this:

"...There is not enough involvement from consumers in Westhill MIND. The people who are involved are encouraged, but I think more people could be encouraged to be involved."

(Interview. Staff member, Westhill MIND)

"...The large number of professionals frightens away consumers from the Executive Committee."

(Interview. Professional Chairperson, Westhill MIND.)

In contrast, in Eastvale MIND, there was a wide range of views about the numbers of consumers and mental health professionals on the Executive Committee. Table 7.2 contrasts the views of Executive Committee members in the twoLocal Associations (70).
TABLE 7.2

VIEWS ON CONSUMER INVOLVEMENT AND PROFESSIONAL INVOLVEMENT IN EXECUTIVE COMMITTEE

<table>
<thead>
<tr>
<th>EASTVALE CONSUMER INVOLVEMENT</th>
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<th>EASTVALE PROFESSIONAL INVOLVEMENT</th>
<th>WESTHILL PROFESSIONAL INVOLVEMENT</th>
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<td>E.C/STAFF</td>
<td>E.C/STAFF</td>
</tr>
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<td>3</td>
</tr>
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<td>9</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

Len, the Secretary of Eastvale MIND, commented:

"...We offer the facility of eight day centre members to join which gives them some voice...it's out of fifteen members, so the majority..."

(Interview. Secretary, Eastvale MIND).
Some respondents referred to the value of having day centre members on the Executive Committee because their viewpoint was respected, but Len commented that some of them lost interest and stopped attending meetings, and it was "difficult filling in places with other day centre users. The facility is there but not taken up" (71).

Most respondents who could answer the question on consumer involvement in Eastvale MIND's Executive Committee felt that there was enough. However, three respondents thought there were too many day centre members on the Committee. One respondent considered that their participation might exclude other people.

Although many Westhill respondents felt there were too many professionals on the Executive Committee, the majority felt that there was some place for a certain amount of professional involvement at this level, although criticisms were made of the type of involvement. A number of people in both Local Associations commented that some professionals on their Committees did not offer enough time or commitment. A few respondents referred to the value of professionals' skills and experience, and/or stressed that these participants should not dominate the Executive Committee, either numerically, or in the way they played their role. One Zeta Club member said "the occasional professional would be all right, because then you get a proper set up: the right blend." Views on professional involvement in Westhill MIND ranged from a few (mainly Delta Club members) who were strongly for professional leadership, to those who were strongly opposed (72).
In contrast to Westhill MIND, no Eastvale MIND participants thought there were too many professionals on the Executive Committee, and about equal numbers thought there were "enough" and "not enough". Professional members and the Association's staff thought there was enough professional involvement, whilst most consumer and lay members of the Executive Committee thought this was insufficient. Whilst professionals predominated at Westhill MIND's Executive Committee meetings, two day centre members of Eastvale MIND's Committee felt that professionals' attendance at meetings was insufficient.

Several Eastvale respondents commented on the need for laypeople and professionals with particular skills and viewpoints. The need for a balanced committee, with consumer, lay and professional representatives was emphasised by some Executive Committee members in both Local Associations, particularly Eastvale MIND. "Generally speaking, we try to get a balance", commented the Secretary. Comments on the importance of balance in Executive Committees reflect National MIND's requirement that Local Associations wishing to be affiliated should contain roughly equal numbers of consumers, laypeople and mental health professionals (73).

DEGREES OF CONSUMER INVOLVEMENT

The next part of this chapter considers different degrees of consumer involvement, which were outlined in Chapter 3 of this thesis. It was suggested that degrees of participation could include: "nil", "explanation", "consultation", "direct representation", "equal participation" and "total running of the organisation" (74). In
Eastvale and Westhill MIND, an attempt was made to assess the extent to which respondents perceived consumers as participating in varying degrees of involvement. They were asked to rate the extent to which day centre or club members were consulted by Executive Committees and involved in decision making and responsibility (75), and in some cases, whether consultation and other aspects of participation was "not enough", "enough", or "too much".

The extent to which club or day centre members were consulted or involved in decision making appeared to relate, in part, to the amount of contact that they had with Executive Committee members. In Westhill MIND the latter were never observed to attend the Clubs, and were said by participants not to have any direct involvement in them (76). In contrast, the day centre was frequently visited by Committee officers and members. Five of the latter were also day centre members (77), and another Executive Committee member frequently did steward duties. Len, the Local Association's Secretary, came to the centre nearly every day, chatting to members and playing pool, as well as supervising the work of new staff. Furthermore, the three officers met with members once a month in open meetings.
Tables 7.3, 7.4 and 7.5 show respondents' views on the extent to which Executive Committees consulted Eastvale day centre members and Westhill volunteers and other club members (78).

TABLE 7.3
EXTENT TO WHICH EXECUTIVE COMMITTEE CONSULTS DAY CENTRE MEMBERS

<table>
<thead>
<tr>
<th></th>
<th>DAY CENTRE MEMBER RATINGS</th>
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<td>Average ratings</td>
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### TABLE 7.4
**EXTENT TO WHICH EXECUTIVE COMMITTEE CONSULTS ZETA CLUB MEMBERS**

<table>
<thead>
<tr>
<th>ZETA CLUB RATINGS</th>
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<th>TOTALS</th>
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<td>Marked (3)</td>
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<td>2</td>
</tr>
<tr>
<td>Fair (2)</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Slight (1)</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Nil (0)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Don't Know</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other response</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Average ratings</td>
<td>0.90</td>
<td>1.10</td>
</tr>
</tbody>
</table>

202
## TABLE 7.5

**EXTENT TO WHICH EXECUTIVE COMMITTEE CONSULTS NON-VOLUNTEER ZETA CLUB MEMBERS**

<table>
<thead>
<tr>
<th></th>
<th>ZETA CLUB RATINGS</th>
<th>EXECUTIVE COMMITTEE/STAFF RATINGS</th>
<th>TOTALS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n10</td>
<td>n9</td>
<td>n19</td>
</tr>
<tr>
<td>Very Considerable (4)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Marked           (3)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fair             (2)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Slight           (1)</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Nil              (0)</td>
<td>8</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Don't Know</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other response</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Average ratings</td>
<td>0.11</td>
<td>0.57</td>
<td>0.31</td>
</tr>
</tbody>
</table>
In Eastvale MIND, respondents gave a wider range of scores in rating Executive Committee consultation of day centre members. In Westhill MIND, consultation of volunteers was usually, and of non-volunteer club members always, voted as slight or less, although four respondents interviewed after the Annual General Meeting in May, 1985 commented that consultation of volunteers had increased since the election, at this time, of four volunteers, three of them club members, onto the Executive Committee.

Several Eastvale MIND respondents referred to open meetings which provided a forum for day centre members to give ideas and suggestions to the Executive Committee. Such open meetings were mostly about matters concerning the day centre, and according to the Manager, "every suggestion from the open meeting is agreed by the Committee if possible." One day centre member, an Executive Committee participant, said: "open meetings are quite useful. But they have no power, no vote: just a talking shop." However, this view was exceptional, and not expressed by other participants.

In Westhill MIND, a number of respondents commented on the lack of consultation of non-volunteer club members:

"..They don't consult me, or anyone else: not the lower order of the scale..".

(Interview. Non-volunteer Zeta Club member, Westhill MIND).
"...I don't think they consult consumers unless they turn up at meetings as volunteers, and they don't realise that they are consumers. They're embarrassed in front of volunteers. They are used to using jargon and find volunteers difficult to understand..."

(Interview. Volunteer Zeta Club member, Westhill MIND).

Two Westhill Executive Committee participants felt that consumers' views were represented indirectly through particular Committee members. The Secretary was said to sometimes read out letters from consumers to the Committee and one member represented the views of residents of the Local Association's group homes. A Development Worker commented that the Executive Committee did not themselves consult consumer views, but had "...views of some members foisted on them through the volunteers' support group. They don't actually seek out people to consult." This respondent said that "the initiative for consultation came, not from the Executive Committee, but from consumers and users of the clubs themselves."

IN Volvement in Important Decision Making

Westhill MIND participants were asked about the involvement of volunteer and non volunteer club members in important decision making in general (79). Eastvale MIND respondents were invited to comment on the influence of day centre members on Executive Committee decisions about the Local Association and the day to day running of the centre. A smaller number of respondents was also asked about consumers' influence on fund raising and decisions concerning the computer (80).

Table 7.6 indicates responses of Westhill MIND participants.
### Table 7.6

**Extent to Which Zeta Club Members Are Involved in Important Decision Making in Westhill Mind**

<table>
<thead>
<tr>
<th>Involvement of Volunteer Members</th>
<th>Involvement of Non-Volunteer Members</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>n17</td>
<td>n19</td>
<td>n36</td>
</tr>
<tr>
<td>Very Considerable (4)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Marked (3)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fair (2)</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Slight (1)</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Nil (0)</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Don't Know</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Average ratings:
- Volunteer: 1.00
- Non-Volunteer: 0.65
- Totals: 0.81

The few respondents interviewed after the 1985 Annual General Meeting commented that volunteers' involvement in important decision making had increased with the election of four volunteers to the Executive Committee.
"...because they're there, they're having a much stronger impact on the Executive Committee than previously and hopefully, a much stronger link with the volunteer group."

(Interview. Executive Committee member, Westhill MIND).

Two Zeta Club participants said that the Local Association's first Development Worker had represented the interests of volunteers and other club members.

"...In the past, [the former Development Worker] had represented volunteers, and as a result, changed the Association from middle class do-gooders to a more flexible, informal organisation. Since he left, it looks as if it has gone back to how it was before. Now we have volunteers on the Executive Committee, theoretically volunteers should have more access to decision making."

(Interview. Zeta Club member, Westhill MIND).

(Interviewed after the election of volunteers onto the Executive Committee, in May 1985).

Three respondents commented that non-volunteer club members' view were represented by volunteers. and two of these remarked on a distance between Executive Committee and club members.
"..the Executive Committee do not listen to consumers, other than hearing their views represented by volunteers, which often happens. Consumers find it difficult to express views, partly because of language and jargon, though volunteers have a foot in both sides and understand jargon. It's a Them and Us situation, and the Executive encourages it..

"..Executive Committee members don't have much contact with club members. People at the top are the sort who can detect their inability to express themselves..

(Interviews. Zeta Club members, Westhill MIND)

Two Executive Committee members questioned non-volunteer club members' interest in being involved: "..They don't come. We did ask..someone to come.. but no-one [attended]."

There were mixed views on the extent to which day centre members influenced decision making in Eastvale MIND, and on whether this was sufficient. Most day centre members said that they could not assess this in relation to Executive Committee decisions about the Local Association. The majority of this group of respondents felt that member involvement in decisions about the day to day running of the day centre was "fair" or above, although a minority felt that this was "not enough". A number of respondents commented that day centre members had a lot of say in the Local Association, particularly in relation to the running of the day centre. However, overall, there were mixed views about the extent to which day centre members were involved in important decision making compared with other participants.
"...There are more members than non-members [on the day centre subcommittee], so I'd say day centre members have quite a lot of influence."

(Interview. Executive Committee member, Eastvale MIND).

This respondent commented that day centre members usually got things that they required, citing as an example the Executive Committee's decision not to buy a minibus for day trips after a majority of day centre members had voted against this in an open meeting. In contrast, a day centre member on the Executive Committee commented:

"...There was quite a lot of controversy with members over the computer... because it was suggested by some members, not the majority..."

(Interview. Day Centre Executive Committee member, Eastvale MIND).

Other respondents expressed more reservations about the influence of day centre members, compared with other Executive Committee participants.

Committee MEMBER A "Well, they are involved, aren't they, on that Executive Committee?"

Committee MEMBER B "They don't make decisions, do they?"

Committee MEMBER A "They tend to be influenced by the Chairperson. [Their influence is] slight."

(Interview. Executive Committee members, Eastvale MIND).
In Westhill MIND it seemed clear that decisions were made and influenced largely by Executive Committee members and staff. This seemed less clear in Eastvale MIND, and day centre members were asked who had most involvement in important decision making in the Local Association (81). The day centre manager was mentioned most frequently, followed by officers. Four participants referred to "Ben", and one respondent to another day centre member on the Executive Committee. Only once were day centre members in general mentioned as being amongst those with the most involvement in important decision making (82).

**TABLE 7.7**

**PEOPLE MENTIONED BY DAY CENTRE MEMBERS AS HAVING THE MOST INVOLVEMENT IN IMPORTANT DECISION MAKING IN EASTVALE MIND.**

<table>
<thead>
<tr>
<th>PARTICIPANTS</th>
<th>NUMBER OF TIMES MENTIONED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day centre manager</td>
<td>11</td>
</tr>
<tr>
<td>Chairperson</td>
<td>8</td>
</tr>
<tr>
<td>Secretary</td>
<td>6</td>
</tr>
<tr>
<td>Treasurer</td>
<td>5</td>
</tr>
<tr>
<td>&quot;Ben&quot; (Day centre member of Executive Committee)</td>
<td>4</td>
</tr>
<tr>
<td>Other answer</td>
<td>3</td>
</tr>
</tbody>
</table>
One day centre member felt that Ben had too much influence, but the majority of respondents indicated that they were happy with the way in which decisions were made and the amount of influence of different participants.

"..Management..should have the main say.."

"..I might have an idea, but at the end of the day, it's up to [the staff] office to decide.."

"..Chairperson, Treasurer [have the most influence], and I think it's in good hands with those because I like both of them. They've got the right idea. I think it should finally rest with them.."

"..Without Chairperson and Treasurer, present Manager and Secretary, we wouldn't get very far.."

(Interviews. Day Centre members, Eastvale MIND).

One day centre member of the Executive Committee felt that important decisions tended to be made by the day centre subcommittee, rather than by the Executive Committee; and that the three day centre members of the former had little power compared with the three officers and the day centre manager, who were the other subcommittee members.
"...The day centre subcommittee... seem to have overall say in what is going on. ...There hardly seems point in having the Executive Committee at all. It's just a talking point: no real decisions made. It would be fairer if there was one committee meeting with everybody there. Also better because views and opinions would be put forward and more of them, so...there would be more insight into views and more democratic.

(Interview. Day Centre Executive Committee member, Eastvale MIND).

Westhill MIND respondents were asked to assess the involvement in responsibility of volunteers and other club members (83). There was a wide range of views on the involvement of volunteers, although the modal response was "slight". Only two respondents felt that other club members were more than slightly involved in responsibility. Three Executive Committee participants were unable to answer this question. All but one of the respondents who felt able to give an opinion thought that there was "not enough" involvement in responsibility of non-volunteer club members, but five respondents felt that this was "enough" or "too much", in the case of volunteers. (Table 7.8).
### Table 7.8

**Respondents' Ratings of Club Participants' Involvement in Responsibility**

<table>
<thead>
<tr>
<th>Rating</th>
<th>Volunteers</th>
<th>Other Club Members</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n18</td>
<td>n19</td>
<td>n37</td>
</tr>
<tr>
<td>Very considerable</td>
<td>(4) 2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Marked</td>
<td>(3) 4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Fair</td>
<td>(2) 2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Slight</td>
<td>(1) 7</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Nil</td>
<td>(0) 0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Other response</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Average ratings</td>
<td>2.07</td>
<td>1.15</td>
<td>1.64</td>
</tr>
</tbody>
</table>
Several respondents commented on the amount of responsibility which volunteers, including club members, took on in various aspects of the Local Association's work. One staff member felt that volunteers were sometimes used to cover staff shortages, and an Executive Committee member commented after the main period of fieldwork:

"...they carry a lot of responsibility for the management of the Resource Centre, in that they man the building, answer calls...do all the hard graft. If responsibility in that sense, "enough". If anything, too much, in that they are asked to do things that are quite difficult. ...And they're getting involved in campaigning and publicity."

(Interview. Executive Committee member, Westhill MIND).

One respondent commented that volunteers' involvement had been very considerable in the clubs, but that, until the Annual General Meeting in June 1985, there had been no volunteer involvement in the Executive Committee. A volunteer club member said that volunteers "...have no power or status, which means that although they are responsible, they report back to the Executive Committee who have true responsibility.".

Some respondents referred to lack of communication between Executive Committee and volunteers and club members. One staff member said that volunteers tended to "go off and do their own thing", without waiting for their activities to be agreed by the Committee. Another respondent, interviewed after the main period of fieldwork, said that attempts were
being made to improve communication by convening a meeting of Executive Committee members, club members and volunteers. This respondent commented: "It's not just the Executive Committee, it's the feeling that volunteers do not want to be involved in committees..."

Whilst most respondents felt that non-volunteer club members' involvement in responsibility was "slight", a few participants felt that this varied, depending on the individual. It was said that the volunteers group was open to anyone who wanted to join it, and two respondents pointed out that some club members did not want to take on responsibility.

**GENERAL QUESTIONS ON CONSUMER INVOLVEMENT**

Finally, some respondents were asked a few general questions on consumer involvement. These concerned their views on: Executive Committee decisions with which a majority of day centre or club members did not agree; decisions in which these participants should not be involved; and whether the Local Association should be run entirely by consumers (84).

In both Local Associations, a majority of respondents said that there had been no instances where day centre or club members had disagreed with the Executive Committee, or that any disagreements had been minor. Most Eastvale MIND respondents indicated that, despite occasional disagreements on minor issues, there was general agreement between Executive Committee and day centre members. One day centre member on the Committee had a number of criticisms of the way in which decisions
were made, but concluded:

"...if the day centre agrees on it, it's almost through as past, because the bulk of the Executive Committee are day centre members..."

(Interview. Day Centre Executive Committee member, Eastvale MIND).

The Chairperson commented:

"...No [disagreements]...as far as I know. If they did [disagree], they could reverse it, could bring it up at an open meeting. Most people can accept our decisions about the Centre as reasonable..."

(Interview. Chairperson, Eastvale MIND).

An Executive Committee member pointed out that if day centre members were not in sympathy with Executive Committee decisions, they would not turn up. "On the whole most members are happy with it". This view contrasted with one day centre member's comment that she knew of some people with depression who did not attend the Day Centre because they felt it did not meet their needs.

The only two Eastvale respondents who were very critical of the Association both left during the period of fieldwork. Unusually, they were very unhappy about communication between Executive Committee and
day centre members, and other aspects of the Local Association. One of
them felt that, regardless of day centre members' wishes, the Committee:

"...will still do what they want to do. I believe the Centre is run
for the benefit of staff and Executive Committee... rather than
members."

(Interview. Local Association participant, Eastvale MIND) (85).

However, this view was unusual. Other respondents' comments on
disagreements, mentioned by a few people, usually concerned practical
matters, such as whether the day centre should have a television or
computer, and how games should be organised.

In Westhill, several participants commented that there was a lack of
disagreement between Executive Committee and club members, partly
because of a lack of communications between the two groups. A staff
member commented: "...Zeta Club members probably wouldn't even know what
decisions had been made..."Four Executive Committee respondents said
that they had not heard of disagreements because they rarely or never
met club members.

"...not heard of any, partly because, although I'm an officer of the
Executive Committee, I know little at first hand of various
activities."

(Interview. Executive Committee Officer, Westhill MIND).
"...because there's no consultation, I'm really not aware of any major disagreements..."

(Interview. Executive Committee member, Westhill MIND).

These views contrast with the view of the Chairperson of Eastvale MIND that any disagreements could be resolved through discussion in open meetings (86). In Westhill MIND, there were few reported instances of disagreement between Executive Committee and club members. However, disagreement appears to have increased after the main period of fieldwork, when four volunteers were elected to the Executive Committee, and attempts were made to increase communication between different participants. At this time a staff member commented that there were "...plenty of decisions made by the Executive Committee which volunteers and users do not agree with...".

Respondents in Eastvale MIND were asked whether they thought there were any decisions in which day centre members should not be involved. Responses were mixed, with about half the respondents feeling that this applied to few or no decisions, and about the same number stating that there were certain issues which should be decided only by staff, the Executive Committee, or its officers. Some respondents gave unequivocal approval for the involvement of day centre members in all decisions. Others commented on the impracticability of involving everyone in decisions or felt that the participation of consumers should depend on their ability and the extent to which this was affected by personal problems or mental illness (87).
Respondents who felt that day centre members should not be involved in all decisions gave a wide range of examples of this. Three day centre members felt that rules concerning the day centre should be made by the Manager:

"..Members should be reprimanded for misdemeanours and if it persists, .. banned.. sent a letter or brought before the Committee .. Management should run the place, they should decide what to do."

(Interview. Day centre member, Eastvale MIND).

One of the Local Association's officers felt that certain aspects of Eastvale MIND's work, such as the new befriending service should be decided by staff, whilst another Executive Committee participant considered that people's involvement in developing Local Association services should depend on their ability, rather than whether or not they had had consumer experience (88). Day centre members (apparently those on the Executive Committee) had been involved in appointing staff, and the Chairperson commented: "some day centre members are very good.." They're much better telling whether people are sympathetic towards them and whether they relate to them". However, two other respondents felt strongly that day centre members should not be involved in this area, and three Executive Committee participants said that there might be some confidential matters concerning day centre members which their peers should not know.
The Local Association's officers felt that certain areas could not be influenced by day centre, or indeed, Executive Committee members, because they were the province of the Manpower Services Commission or the local Health Authority. The chairperson and treasurer acted as sponsors to the Manpower Services Commission, and were responsible to this body for "the running of the project according to rules laid down by the Manpower Services Commission and the safe custody of financial affairs" (89). The Chairperson said that, in exceptional circumstances, it might be necessary for the sponsors to "overrule the Committee", but that this had happened on only one occasion, and other participants were involved "as much as possible". In addition, a few respondents felt that it was not always possible to involve all members in some financial matters; and the Secretary of the Association mentioned that Health Authority and Health and Safety rules required that basic safety precautions were observed: eg., in the use of the day centre's microwave. This limitation of consumer involvement because of the requirements of external bodies is reminiscent of literature which describes ways in which bureaucracies or the wider society have placed boundaries on permissiveness and on residents' involvement in decision making in therapeutic communities (90).

As far as could be ascertained, no day centre members had ever been appointed as officers of the Association. The reasons for this are unclear (91). One day centre member on the Executive Committee said that he had once offered to become secretary when this post was vacant, but had been turned down by the Committee. Other day centre members had
wanted to nominate him as Secretary at the 1984 Annual General Meeting, but he had decided not to stand for this post in case he lost, and then did not have a place on the Executive Committee.

Respondents were asked their views on consumers' applications for funding and on total consumer involvement in the running of the Local Association, including the occupation of officer and staff posts (92). Comparatively few respondents in either Local Association gave an unequivocal "Yes" to the former question. A small number could see no reason why consumers should not apply for funding, but the majority had reservations about this, and felt that in certain instances it was not a good idea, or that such applications would not be seriously considered. One respondent felt that some people with consumer experience would be able to apply for funding, but doubted whether day centre members were sufficiently articulate. Several respondents commented that consumers' success in acquiring funding depended on factors such as their skills, articulateness or extent of mental illness (93), but two respondents, with senior positions in Social Services (94), felt that applicants' experience of mental health problems was not an important factor to consider in statutory allocation of funds to voluntary organisations.

TOTAL CONSUMER INVOLVEMENT

In considering whether it would be possible for the Local Association to be entirely consumer run, only one respondent in Eastvale MIND gave an unequivocal "Yes", compared with eight people in Westhill MIND. About equal numbers in both Local Associations gave unequivocal "No's" to this question. Views from club members included:
"...I think they should, because they are the people who know more about it. When you've been through it, you know what it's about..."

(Interview. Delta Club member, Westhill MIND).

"...Yes..because my illness never affected my work one little bit. If someone knew I was ill, they'd assume I couldn't take the pressure. This is not so. It can affect you in different areas..."

(Interview. Zeta Club member, Westhill MIND).

A variety of views for and against consumer involvement in the Local Associations was expressed, with rather more disadvantages than advantages being mentioned. Proponents referred to the value of consumers' abilities, their personal experience of mental health problems and services, and the fact that such experience did not necessarily impair individuals' ability to participate. In contrast, several respondents felt that total consumer involvement would be difficult because some people's mental health problems could make it hard for them to take on responsibility. Several respondents commented that whether their Local Association could be entirely consumer run would "depend on the consumers" concerned and one Executive Committee member felt that, whilst consumer run organisations were possible, this could not happen in Eastvale MIND.
"..I think it's possible, but not people at Eastvale MIND. People who do get over mental health problems one hundred percent could run MIND: people who improve and are successful."

(Interview. Executive Committee member, Eastvale MIND).

A few respondents felt that to have only consumers in the Local Association would lead to a lack of objectivity or balance, and stressed the need for a variety of views (95). Some people felt that the Local Association did not aim to be a consumer-run organisation, but one which, in the words of one Westhill Executive Committee member, aspired to be:

"..a partnership group. I think it is very complex. With our Local Association, there needs to be some professional input. Some voluntary organisation [consumers] do run themselves, eg, self help groups, but it relates to the nature of the group, its aims and complexities..."

(Interview. Executive Committee member, Westhill MIND).

The majority of respondents in both Local Associations was in favour of consumer involvement, and in Westhill MIND, in particular, of increasing it. But for most participants, particularly in Eastvale MIND, this did not extend to a belief that consumers should completely run the Local Associations themselves.
Before summarising the main findings outlined in this Chapter, reference will be made to the conceptual problems which were encountered, and to ways in which the study of Eastvale and Westhill MIND enhanced my understanding of the complexity of the terms "consumer" and "consumer involvement". In chapter 3 reference was made to the complexity of consumer involvement as a concept, with many types, levels and degrees (96). In early fieldwork, I made a number of assumptions about the nature and meaning of "consumer" and "consumer involvement". These included the belief that Local Association participants could be readily identified as "consumers", "lay people" (97) and "mental health professionals". This assumption ignored participants' own perceptions of the reasons for their involvement. Later fieldwork in Local Associations found that some participants saw themselves as having more than one of these roles, with variations in the extent to which their own consumer experience was a reason for their participation (98).

However, my assumption that Local Association participants could easily be categorised into three groups seemed to be shared by many participants. Eg. in pilot interview, a few respondents, when asked about consumer involvement, went through lists of Executive Committee members, making comments such as: "she's a social worker, he's been mentally ill.".
Another assumption early in the study was that Local Associations catered for consumers in the narrow sense of people who had, themselves, had mental health problems, and/or used mental health services, rather than for all members of a local community as potential or actual consumers. In pilot interviews, two Local Associations, including Westhill MIND, were found to run clubs whose membership was for everyone, rather than for people with identified mental health problems (99).

Another weakness of the study was the failure to assess whether Eastvale participants viewed themselves as day centre members and what constituted such a role. I assumed that some people attending the centre were clearly delineated "day centre members", and that people who occupied other roles (e.g. "volunteer" or Executive Committee Officer") did not attend primarily to meet their own needs. This assumption seemed to be shared by participants. E.g., Len, the Local Association's Secretary, who frequently visited the Centre and chatted and played games with members, was seen by others, and by himself, as "Secretary", and not as "member". The women who attended the weekly fund raising Bingo sessions were seen as "visitors" rather than "members" despite the satisfactions that they apparently gained from the Bingo. My assumption that day centre members could easily be distinguished from other people failed to take account of the extent that participation met the psychological and social needs of all participants, (including those who did not see themselves as "day centre members"). An argument could be made for perceiving all participants in a Local Association as being consumers of that Association if their involvement fulfilled such needs.
Respondents often mentioned day centre members in a way which indicated their perception of the discreteness of the category, and public statements about Eastvale MIND's aims referred explicitly to day centre members and to providing resources for people with, or recovering from, mental illness (100). Westhill MIND's Annual Report also described services in a similar way (101), but in the Clubs I became aware that participants could not easily be categorised into "consumers" and "lay volunteers", and respondents were asked how they perceived their participation.

Reference has been made to the complexity of consumer involvement and the variety of degrees and levels that exist (102). Rating scales, particularly those used in pilot interviews, attempted to reflect this, but also mirrored my biased assumptions about what constituted consumer involvement, and ways in which it could be measured (103). Another weakness is that questions concerning decision making and responsibility lacked clear formulations of these terms and tended to equate consumer involvement with fairly formal participation. Whilst this had some truth in Eastvale MIND, in the Clubs, particularly Zeta, involvement was much more informal, and some respondents saw all participants as both giving and receiving help. Eastvale MIND offered more scope for participation within the Day Centre, with responsibilities being more formalised and subject to certain rules. But in some ways Zeta Club gave considerable scope for "consumer involvement" even though participants did not necessarily aim to increase such participation in a formal sense, or to distinguish between consumers and other participants (104).
SUMMARY AND CONCLUSION

A comparative study was made of two Local Associations which apparently differed in the extent and nature of consumer involvement. Eastvale MIND offered more scope for such participation in the formal sense, with specific clearly "visible" roles and responsibilities which involved some accountability. In Westhill MIND's Clubs there was little distinction between consumers and other members. All participants could be as involved as they wished, and there was an overlapping of roles (105). In Eastvale MIND, decisions tended to be made in a relatively formal way through various meetings, but in the Clubs, there were relatively few specific decisions and things usually just "happened".

Eastvale MIND's Executive Committee had participants from a variety of backgrounds and included five day centre members, but all of Westhill's Committee were professional people, none of them, apparently, with consumer experience. In Westhill MIND, dissatisfaction was expressed about what was perceived as an excess of professional participation and a lack of consumer involvement in the Executive Committee, and attempts were made to increase the latter. In contrast, Eastvale MIND respondents were, overall, more satisfied with the extent of consumer involvement, but some would have liked more professional participation in the Executive Committee.
Westhill MIND respondents felt that there was very little consultation of club members, or involvement of the latter in important decision making. These components of consumer involvement were given an average rating of "fair" by Eastvale respondents, and a wider range of views was expressed. Most Westhill MIND respondents felt that club members' responsibility in the Local Association was limited.

There were said to be few areas of disagreement between Executive Committee and club/day centre members. Views differed on whether there should be any areas in which day centre members should not be involved.

Most respondents expressed reservations about consumers' abilities to successfully apply for funding, and whilst the majority seemed in favour of consumer involvement most felt that the Local Association should not be entirely consumer run. In Eastvale MIND most respondents saw participants who were not day centre members as having the most influence on decision making. No day centre member in Eastvale MIND had, apparently, been appointed to an officer post, and consumer involvement in this Local Association did not extend to the management of the organisation.

Finally, the study of the Local Association led to modification and extension of ideas and assumptions formed in early fieldwork; and supported findings from a survey of the literature (106) that "consumer, and "consumer involvement" are complex concepts, and that the latter can occur at a variety of degrees and levels.
So far, this thesis has examined the growth of an interest in increasing consumer involvement in MIND at different levels, and the nature and extent of such participation, particularly in the National office and in two Local Associations. The next two chapters examine, with reference to relevant literature, the benefits and problems of consumer involvement in MIND, and in the other voluntary organisations which were studied.

In the literature, consumer involvement is described as resulting in both benefits and problems to the individual participant, to other consumers, and to the organisation itself. Benefits to the individual are said to include psychological gains, such as increases in confidence, self esteem, fulfilment and self determination (1); the acquisition of skills, knowledge and practical experience (2), and increased awareness (3); increases in participants' power and collective strength (4); and in their sense of responsibility and commitment (5). Participation has also been said to indicate belief in the worth of the individual (6), and to be of value in its own right (7).
Various problems to the individual from her/his participation have also been described. Consumer involvement has been said to be difficult both because of the complexity of some organisations (8), and as a result of participants' lack of confidence, skills, knowledge or motivation (9). Some writers argue that participation is often under the control of those in authority (10), and fails to result in appreciable shifts in power (11), with a denial of any political or other interests involved (12), and the support of the status quo (13). The problems of the representativeness of consumers who participate (14), and differing interests amongst consumers, and between consumers and other people, have also been described (15).

Some authorities have commented on the difficulties of assessing the benefits and problems of participation. Thus, Richardson and Goodman comment that "...problems seen from one point of view may not be so described from another". (16). Windle and Cibulka state that little is known about the effectiveness of consumer involvement (17), whilst Hughes concludes that "...there is no simple equation between participation and the fulfilment of basic needs." (18).

THE VIEWS OF MIND RESPONDENTS

In interviews, most MIND respondents were asked their views on the benefits and problems of consumer involvement, both to the individual participant and to the organisation as a whole (19). Individuals who were asked this question included members of Council of Management, National MIND staff, and volunteers, members of Forum, Regional MIND staff, day centre/club members and Executive Committee participants in Eastvale and Westhill MIND (20). Respondents in the other
voluntary organisations studied were also asked about the benefits and problems of consumer involvement in their organisations (21).

In addition, participants in Local MIND Associations with high consumer involvement were asked questions on this topic (22). Regional MIND staff were asked to indicate which Local Associations had the greatest amount of consumer involvement in their Region (23). Of these, half (ten) were chosen for study, in order to increase understanding of consumer involvement, particularly in relation to its nature, extent, associated benefits and problems, and factors which facilitated and hindered such participation. These Local Associations were chosen for study as "case examples" (24) of organisations with high consumer involvement. Because of constraints of time, they were mostly selected on the basis of geographical accessibility to Regional MIND offices, rather than at random, so that interviewing of both Local Association and Regional participants could easily be combined (25). It was decided not to select those Local Associations with the very highest amounts of consumer involvement, not only for reasons of accessibility, but because such participation would have been difficult to measure, given its complexity (26).

Overall, MIND respondents mentioned more benefits than problems to consumers from their involvement in the organisation. Tables 8.1 and 8.2 indicate those which were most frequently mentioned (27). Many respondents mentioned more than one benefit and/or problem (28).
**Table 8.1**

**Most Frequently Reported Benefits to Consumers from Their Participation in Mind**

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Consumers</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological gains</td>
<td>19</td>
<td>10</td>
<td>29</td>
</tr>
<tr>
<td>Feeling valued/of use</td>
<td>22</td>
<td>8</td>
<td>30</td>
</tr>
<tr>
<td>Responsibility and decision making</td>
<td>21</td>
<td>3</td>
<td>24</td>
</tr>
<tr>
<td>Gains from giving or receiving help</td>
<td>14</td>
<td>8</td>
<td>22</td>
</tr>
<tr>
<td>Empowerment and choice/ability to bring about change</td>
<td>10</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Extrinsic rewards</td>
<td>7</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Intrinsic interest of participating activities</td>
<td>8</td>
<td>0</td>
<td>8</td>
</tr>
</tbody>
</table>
TABLE 8.2

MOST FREQUENTLY REPORTED PROBLEMS TO CONSUMERS FROM THEIR PARTICIPATION IN MIND

<table>
<thead>
<tr>
<th>Problem</th>
<th>Consumers</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty taking on responsibility/making decisions</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Different views/perspectives of other participants</td>
<td>8</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Organisational factors</td>
<td>8</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Not feeling valued/of use</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Lack of skills/abilities</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Lack of real power/ability to make changes</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Lack of help/support from others</td>
<td>5</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Lack of extrinsic rewards</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

n 59  n 65  n 124
Whilst respondents mentioned psychological gains, feeling valued and of use, benefits related to involvement in responsibility and decision making, and gains from giving or receiving help, smaller numbers of participants referred to problems in these areas. Extrinsic rewards from participation or their lack were not much referred to in the literature surveyed, but were mentioned by several (mainly National) MIND respondents (29). Several participants referred to the empowerment of consumers as a benefit and/or problem of participation, and there were mixed feelings about whether consumer involvement in the organisation resulted in real increases of power for consumers, or not (30).

Overall, respondents reported more benefits than problems to consumers from their participation, and about equal numbers of benefits and problems to the organisation and other participants (Table 8.3). The latter are detailed in Tables 9.1 and 9.2.

In interviews with National MIND participants, volunteers, who had all had consumer experience, reported more benefits than problems from their involvement, whilst other respondents mentioned a greater number of problems to the individual consumer. In both Eastvale MIND and Westhill MIND, particularly the former, consumer involvement was described as having more benefits than problems to consumers, but in Eastvale MIND there were fewer references to benefits to others, and to the Local Association as a whole. In Local Association with high consumer involvement roughly equal numbers of benefits and problems, both to the individual, and to the Local Association as a whole, were described in interviews (31).
<table>
<thead>
<tr>
<th></th>
<th>National/Regional Mind</th>
<th>Eastvale Mind</th>
<th>Westhill Mind</th>
<th>Local Associations with High Consumer Involvement</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers Partici-</td>
<td>9</td>
<td>15</td>
<td>9</td>
<td>17</td>
<td>9</td>
</tr>
<tr>
<td>pants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Participants</td>
<td>28</td>
<td>18</td>
<td>16</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>Benefits to the</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>individual</td>
<td>37</td>
<td>18</td>
<td>34</td>
<td>16</td>
<td>126</td>
</tr>
<tr>
<td>Problems to the</td>
<td>18</td>
<td>8</td>
<td>20</td>
<td>11</td>
<td>62</td>
</tr>
<tr>
<td>individual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits to the</td>
<td>5</td>
<td>7</td>
<td>7</td>
<td>8</td>
<td>45</td>
</tr>
<tr>
<td>organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems to the</td>
<td>4</td>
<td>19</td>
<td>12</td>
<td>11</td>
<td>34</td>
</tr>
<tr>
<td>organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 8.3**

Numbers of Benefits and Problems from Consumer Involvement Reported by Respondents.
The rest of this Chapter describes the various benefits and problems of consumer involvement in more detail.

THE SALIENCE OF CONSUMER INVOLVEMENT

Firstly, an examination will be made of the extent to which consumer involvement was a salient issue to MIND participants during the period of fieldwork. The terms "salience" refers here to the degree of importance which participants attached to consumer involvement. A number of studies have described the lack of salience of participation for consumers in organisations which have encouraged their involvement, or the apathy of potential participants (32). In the words of Hughes "...not all political cultures or individuals rank participation highly among their social needs." (33).

In considering consumer involvement in MIND, it should be remembered that unlike the other voluntary organisations which were studied, MIND was concerned, at all levels of the organisation, with a wide range of professional and public, as well as consumer interests. MIND literature and respondents' views indicate that MIND was perceived as an organisation which welcomed the participation of professionals, laypeople and consumers (34). Most respondents did not feel that MIND should be run entirely by consumers (35), but almost all said they were in favour of increasing the amount of consumer involvement in the organisation.
To determine the extent to which consumer involvement was salient to participants overall, it is necessary to consider the data, an analysis of which suggests that consumer involvement was of considerable significance to some participants, and of less significance to others.

Four factors indicate that consumer involvement was salient to some participants:

1. The increasing number of references to consumer involvement in Annual Reports of National MIND from the early nineteen eighties suggests that at least some participants wished to present MIND as having an interest in this issue (36).

2. Most respondents expressed broad agreement with attempts to increase consumer involvement, although many qualifications and reservations were expressed. The majority of respondents in Local Associations with high consumer involvement expressed support for their relatively high participation of people with personal experience of mental health problems, with particular enthusiasm being expressed by those consumers who were involved to a considerable extent. In Eastvale MIND the majority of respondents agreed with attempts to involve consumers: eg, election to the Executive Committee, and monthly meetings with all day centre members, although there were some reservations, with a number of participants favouring more professional, and in a few cases, less consumer involvement. A minority of day centre members did not appear to see consumer involvement as a particularly salient issue. In
National MIND, Regional offices and Westhill MIND, most respondents expressed support for attempts to increase consumer involvement at their levels of the organisation. The topic had been considerably debated amongst National MIND staff and Council of Management members, in some Regional offices and in meetings of Westhill MIND, with an examination of ways in which consumer involvement could best be implemented (37). Nevertheless, some respondents expressed reservations. Thus, of thirty National MIND participants who were asked what they thought of recent suggestions that there would be more consumer involvement in MIND (38), nineteen agreed, eight with reservations. No respondent expressed unequivocal disagreement, but eight participants gave mixed views, had no particular view or did not directly answer the question, and three people gave "don't know", answers.

3. Most respondents saw consumer involvement as a priority, although at National level, in particular, a few participants felt that there was limited commitment to implementing consumer involvement as opposed to discussing it (39).

4. Most respondents reported more benefits than problems to consumers from their participation, and some individuals, particularly in Local Associations with high consumer involvement, were enthusiastic and wished to contribute something to others on the basis of their own experience (40).

However, other factors indicate that consumer involvement was not particularly salient to some participants:
1. Very few people mentioned consumer involvement, either as a main aim of National MIND or of Eastvale and Westhill MIND, or in the case of the latter, an aim which they would like their Local Association to have.

2. Few users of Eastvale and Westhill MIND services mentioned consumer involvement in describing what they liked or disliked about their centre or club, the Local Association or their responsibilities in the organisation.

3. Few respondents, except for those in Local Associations with high consumer involvement, said that they joined because of a wish to participate in decision making and responsibility (41).

4. Local Association participants who were involved because of their consumer experience did not usually wish for further participation: eg. at other levels of the organisation, and often did not see Regional and National concerns as particularly relevant to them.

5. A number of respondents commented that some people with consumer experience did not want to participate because of lack of motivation, which was sometimes ascribed to individuals' mental health problems (42). Accounts have been given of the lack of participation of consumers in organisations which encourage their participation (43), and the problem of some consumers becoming burdened with responsibilities which others are reluctant to share because of apathy or the lack of salience of consumer involvement (44).
However, data from interviews and participant observation suggest that the lack of mention of consumer involvement as an aim, or as a reason for liking or disliking the Local Association or its activities and responsibilities, may have been affected by factors other than a lack of salience.

Firstly, a few National MIND respondents indicated that they saw consumer involvement as intrinsic to many aspects of the organisation's work, rather than being a separate aim in itself.

Secondly, in Eastvale and Westhill MIND, whilst most day centre and club members were involved in some sort of responsibility, this was not often an important reason for them to attend. Of considerably greater salience was the availability of refreshments, games and in the centre, other interesting activities, opportunities to meet people, and, in respondents' words, friendliness and a relaxed atmosphere (45).

Thirdly, whilst most respondents (particularly those in National MIND, Regional offices, Westhill MIND and many Local Associations with high consumer involvement) saw such participation as a valued end or goal in itself, for others (especially those in Eastvale MIND) it was a means to an end: a way of achieving desired goals. Much of the literature distinguishes between participation as an end in itself, and its use to achieve particular goals (46). For some respondents such goals included increases in self-confidence, responsibility and empowerment. This is reminiscent of much writing on therapeutic communities, which stresses the value of participation in enabling residents to achieve autonomy and the ability to take on responsibility (47). Other respondents,
particularly Eastvale MIND participants, emphasised the value of consumer involvement in leading to goals which were of benefit to others in the organisation, such as fund raising and services used by others. Whilst the intrinsic value of consumer involvement was recognised by Eastvale MIND respondents, a few participants stated that some of the work was done by day centre members because of a shortage of staff and non consumer volunteers (48).

Finally, much consumer involvement seemed to be "taken for granted" by some participants, who were involved in various activities without being particularly aware that what they were doing was "consumer involvement". A contrast can be drawn between two groups of participants. The first group, including, in particular, some members of Local Associations with high consumer involvement, were conscious that they were engaged in, or facilitating such participation. These people emphasised that their own, or others' experience was important as a means to understanding and giving to others with similar experiences. Some of them wished to empower consumers and/or influence or change mental health services. A second group of MIND participants got on with various tasks without being conscious that they were engaging in "consumer involvement". In interviews they did not express the view that their contribution was based on their consumer experience. Consumer involvement seemed to be "taken for granted" by many of these participants: something which was largely unremarked, unconceptualised (49). An example of this was given by a National MIND staff member who said that a Local Association participant had rung her to ask about a Workshop on consumer involvement which National MIND was running for Local Associations. She asked the staff member what consumer involvement
meant, and on being told, exclaimed: "Oh that: We've been doing that sort of thing for years in our Local Association, but we don't call it that" (50). A similar view was expressed by a respondent in one of the Local Associations with high consumer involvement, who remarked that attempts to assess consumer involvement imposed a "reality" onto something which no one in her Association had formulated, or thought about in particularly precise terms (51). However, such views were unusual, and most respondents could readily identify benefits and problems of consumer involvement. These will now be considered in turn.

EXTRINSIC AND INTRINSIC BENEFITS

In Local Associations with high consumer involvement, several respondents said that they had joined in order to actively participate in the organisation because of their wish to contribute, based on their experience as consumers (52). In contrast, when Eastvale MIND day centre members were asked why they had joined, or what they liked or disliked about the day centre (53), consumer involvement was mentioned by very few respondents, including those who were actively involved in responsibility and decision making within the Association. Instead, most members, as well as some Westhill MIND club participants, stressed the importance of interesting activities, having "somewhere to go", opportunities to meet with, and chat to people, and the availability of drinks and snacks (54). For example, one respondent said she liked the day centre because of:
"...making cuddly toys, yoga ... day trips. There's ... tea or coffee when you ask, and the price is fair. The people who come are all civil and sociable: there's always someone ... you can have a chat with. There's a local fish shop. You can get a bag of chips and eat them [in the centre] ... The girl running it now seems very concerned. I'm highly satisfied with the centre. ... It's always very clean. ... You're allowed to play your own records. There's computer, billiards, something for everyone to take an interest in...".

(Interview. Day Centre Member, Eastvale MIND).

Occasionally, consumer involvement conflicted with the benefits of attending the centre as a member. Thus, two stewards (55) remarked that one thing they disliked about this responsibility was that they had less time to join in games and other activities.

In addition, whilst respondents at all levels of MIND placed considerably more stress on the intrinsic benefits of consumer involvement, a minority, particularly day centre members (56) and National MIND volunteers, emphasised those which were extrinsic. The latter included gains in material comforts as a result of consumer involvement: eg, from the provision of refreshments, small sums of money as payment for tasks (57), or involvement in games and other interesting activities. Intrinsic benefits, mentioned by respondents, included psychological gains to the individual, including increases in confidence, self esteem and empowerment, satisfaction from helping others, taking on responsibility, and developing skills and abilities.
The literature surveyed does not distinguish between the intrinsic and extrinsic benefits of participation, or consider the latter, although some industrial sociologists have done so in relation to paid employment. Thus, workers with expressive attitudes are said to derive satisfaction from the job itself, whilst those with an instrumental orientation work, solely or mainly, for extrinsic satisfactions such as financial reward (58).

Some respondents referred to particular extrinsic benefits which they or other participants gained from consumer involvement. These included, for National MIND volunteers, security and a place to go to during the day. Fifteen out of eighteen day centre members mentioned extrinsic benefits from their active involvement in various responsibilities in the Association. An Executive Committee member of Eastvale MIND felt that day centre members participated in fund raising events in the town because the Committee offered "an inducement . . . like "we will buy your dinner and pay your fare"."

A few day centre members who were Stewards described the benefits of free refreshments and a small allowance paid by the Local Association (59).

"..I liked [being a Steward] because I got four pounds a week . . . made quite a bit of difference and I was allowed to earn it on unemployment benefit."
"... Yes, money helps... But I would definitely do it for nothing because MIND's been very good to me...".

(Interview, Day Centre Members, Eastvale MIND).

A few National MIND respondents also commented on the value to volunteers of extrinsic benefits such as travel expenses, or the lack of sufficient rewards of this kind.

"...Although I appreciate I'm a volunteer, I would like financial compensation. But I get luncheon vouchers and travel, which is excellent..."

(Interview, Volunteer, National MIND).

In contrast, two other volunteers described difficulties in getting fares paid and MIND's refusal to refund the cost of phone calls that they made to the organisation to see if work was available.

"... I don't think they trust us... they won't give us fares. It's unfair. Other people would be paid six pounds an hour [for working]. But if we were paid, they would expect you to come each day, so it's better the way it is... if you came in every day you'd have to have a commitment. Some days you feel ill..."

(Interview, Volunteer, National MIND).
Several intrinsic benefits to consumers from their participation were described by respondents, and the lack of such gains was felt to be a problem by some participants. Intrinsic benefits included increases in psychological well being, such as raised confidence and self esteem, feeling valued and of use, the development of particular skills and abilities, including the capacity to make decisions and take on responsibility, and increased empowerment and choice. Tables 8.4 and 8.5 indicate intrinsic benefits and problems to consumers (60) (pp 246A and 246B).

In the literature a number of psychological benefits from consumer involvement has been described. Hughes comments that "..enhancement of psychic satisfaction is .. difficult to assess." (61), but several authorities describe psychological gains, such as increases in self esteem, confidence, self worth and sense of fulfilment (62), a lessening of isolation (63), and improved mental health in users of mental health services (64). In the present study, local MIND participants stressed psychological benefits to a greater extent, compared with National MIND respondents (65). Several people, particularly in Westhill MIND, felt that consumer involvement was of benefit because it helped raise participants' confidence and self esteem. Although several respondents described such gains in other people, few people said that their involvement had increased their own confidence and self esteem.

"..If club members were to take on responsibility, they would grow in self esteem, and begin to grow in confidence: see themselves as functioning individuals with something worthwhile to decide."

(Interview. Delta Club member, Westhill MIND).
### Table 8.4

Respondents' most frequently reported intrinsic benefits to the consumer from consumer involvement.

<table>
<thead>
<tr>
<th>Psychological gains (e.g., gains in confidence and self esteem)</th>
<th>Feeling valued/of use</th>
<th>Responsibility and decision making</th>
<th>Mutual support/friendship</th>
<th>Empowerment and choice/bringing about change</th>
<th>Increases sense of belonging to, and involvement in, the Local Association.</th>
</tr>
</thead>
<tbody>
<tr>
<td>National/Regional Mind</td>
<td>Eastvale Mind</td>
<td>Westhill Mind</td>
<td>Local Associations with high consumer involvement</td>
<td>Totals</td>
<td></td>
</tr>
<tr>
<td>Consumers</td>
<td>Other Participants</td>
<td>Consumers</td>
<td>Other Participants</td>
<td>Consumers</td>
<td>Other Participants</td>
</tr>
<tr>
<td>n = 9</td>
<td>n = 28</td>
<td>n = 15</td>
<td>n = 9</td>
<td>n = 18</td>
<td>n = 17</td>
</tr>
<tr>
<td>Psychological gains</td>
<td>4</td>
<td>0</td>
<td>4</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Feeling valued/of use</td>
<td>8</td>
<td>1</td>
<td>10</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Responsibility and decision making</td>
<td>5</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Mutual support/friendship</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Empowerment and choice/bringing about change</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Increases sense of belonging to, and involvement in, the Local Association.</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Total participants: n = 124
### TABLE 8.5

RESPONDENTS' MOST FREQUENTLY REPORTED INTRINSIC PROBLEMS TO THE CONSUMER FROM CONSUMER INVOLVEMENT

<table>
<thead>
<tr>
<th>Difficulty in taking on responsibility</th>
<th>NATIONAL /REGIONAL MIND</th>
<th>EASTVALE MIND</th>
<th>WESTHILL MIND</th>
<th>LOCAL ASSOCIATIONS WITH HIGH CONSUMER INVOLVEMENT</th>
<th>TOTALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers</td>
<td>n = 9</td>
<td>n = 28</td>
<td>n = 35</td>
<td>n = 18</td>
<td>n = 18</td>
</tr>
<tr>
<td>Other Participants</td>
<td>n = 1</td>
<td>n = 2</td>
<td>n = 3</td>
<td>n = 4</td>
<td>n = 4</td>
</tr>
<tr>
<td>Consumers</td>
<td>n = 10</td>
<td>n = 17</td>
<td>n = 18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Participants</td>
<td>n = 17</td>
<td>n = 18</td>
<td>n = 18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty in taking on responsibility</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Consumers or their contributions</td>
<td>4</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>insufficiently valued by others</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Lack of skills/abilities</td>
<td>0</td>
<td>1</td>
<td>0</td>
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</table>

Total: n = 124
A few respondents commented that consumer involvement helped individuals to be more assertive and less passive:

"..Amy has made the transition from user to volunteer. She is a lot more confident and more assertive. I think those are very good things."

(Interview. Zeta Club member, Westhill MIND).

Amy herself commented:

"..Taking on responsibility stops you being passive. As well as isolation, passivity is a problem in mental illness."

(Interview. Zeta Club member, Westhill MIND)

In the literature, there appear to be comparatively few references to possible adverse psychological effects of participation, although Algie and Chamberlin describe lack of confidence and low self-esteem (66). In the present study, whilst a majority of respondents felt that consumer involvement increased participants' confidence and self esteem, others described factors within the individual and/or organisation which made this difficult. Problems mentioned included limitations in confidence, ability or motivation, which, it was said, sometimes made it hard for some consumers to take on responsibility, make decisions or put across points in meetings.
The nature of the work which consumers undertake has been said to lead to various psychological benefits, including meeting needs for satisfaction and fulfilment (67), and achievement (68). Opportunities to participate have been described as affirming a belief in the value of the individual consumer and her/his contribution (69). Cahn and Cahn state that participation is "...the necessary concomitant of our faith in the dignity and worth of the individual." (70). Participation in Industry is said to be of importance to the mental health of workers and their satisfaction with work (71), the reduction of alienation and an increased sense of belonging to the organisation (72). In some circumstances, participation can increase motivation and commitment (73).

Some of these views in the literature were reflected in the opinions of many respondents. There seemed to be general agreement that consumer involvement should: a) enable participants to feel valued and of use; b) involve voluntary work and other activities which were satisfying and gave opportunities for responsibility and involvement in decision making. In addition, some respondents commented that participation should raise the status and power of consumers within the organisation.

FEELING VALUED AND OF USE

Several respondents, particularly Eastvale MIND day centre members, said that they valued their participation because it gave them something to do, provided a sense of purpose, and helped them to feel wanted. Some Eastvale MIND participants said that they or other members had joined the Local Association in order to take part in interesting activities in the day centre, which contrasted with their otherwise lonely lives in
bedsits and pubs. Reasons which members gave for joining included "somewhere to come", "to pass the time", "nothing much else to do", "get myself out a bit more". Members did not join in order to participate in decision making and responsibility, but such involvement often grew from their initially taking part in activities in the centre. Volunteers from a Local Association ("Dock Green MIND") indicated that their participation in the National Office also stemmed from a need for something to do and somewhere to go during the day.

Several respondents, particularly in Eastvale MIND, commented that consumer involvement enabled participants to feel wanted and of value, and gave them a sense of purpose.

"..The five day centre members on the Executive Committee were unemployed and wanted something to do occupation wise, but were not well enough to do a full time job. It gives them an interest".

(Interview. Day Centre Member, Eastvale MIND).

"..I know people it's helped. I think the main thing is giving them a feeling of being wanted and useful and making a valid contribution. A lot of MIND's customers just feel like surplus, with no work. They live very empty lives.."

(Interview. Co-opted professional member of Executive Committee, Eastvale MIND).
"..It gives them something to go on for. By involvement in the Centre.. you can feel a sense of achievement. a lot of people here need.. to feel they're wanted, needed, that they're doing something for each other, not doing it just for themselves."

(Interview. Day Centre member, Eastvale MIND).

One day centre member said that he liked his job as Steward because:

"..It's something to do.. do something other than just sit.. the more I do, the less bored I am."

(Interview. Day Centre member, Eastvale MIND).

Some respondents felt that consumer involvement was beneficial because it valued people.

"..They're put in a position of respect, trust. .. We have given a value to their judgements where [previously people didn't] value their views and decisions and just [ignored them]."

(Interview. Staff Member, Local Association with High Consumer Involvement).

Other respondents described ways in which consumer involvement was rendered difficult because consumers were treated in a patronising or invalidating way (74). Some National MIND participants felt strongly that volunteers at Headquarters were not valued because of what were
perceived to be unrewarding, exploitative and demanding tasks (such as routine clerical work). One respondent referred to negative staff attitudes towards volunteers, and another to the latter’s low status and absence of staff planning of their work.

A number of respondents referred to the nature of consumers' voluntary work as resulting in benefits and problems. This topic does not appear to be much mentioned in the literature on participation, but a great deal has been written on the nature of paid employment and ways in which this can be either alienating or fulfilling (75). Workers' participation and its concomitant increase in power has been said to lead to increased commitment and satisfaction with work (76). Several authors have commented on ways in which consumer involvement in public services and in therapeutic communities increase users' sense of responsibility and commitment (77). Respondents had mixed views about the voluntary work undertaken by consumers in MIND, and whether or not this resulted in increased psychological well being, status, power and responsibility. Several people with consumer experience at National and local levels described benefits to consumers from learning to take on responsibility, and in some cases, gaining valuable work experience, but such benefits were rarely described by staff, Council of Management or Executive Committee members. In National MIND, in particular, several (non-volunteer) respondents referred to lack of opportunities for people with consumer experience.
Some respondents saw the opportunity to take on responsibility as being of value in itself. Perceived benefits of responsibility included gains in confidence and self esteem, and preparation for taking on responsibility in work and other situations in everyday life (78). Respondents' comments included:

"...It builds you up to decision making in the outside world. It gets you used to responsibility. I think it's part of the process of leading a normal life to be involved in making decisions and taking on responsibility. I believe it encourages them to take a bigger responsibility in life outside and being independent."

(Interview. Zeta Club member, Westhill MIND).

"...I think responsibility is good for anybody and would be good for me, but I'm too anxious. But I admire people who take responsibilities. Does a lot for their confidence. Makes them inclined to take on responsibilities elsewhere, compared with people who are in a rut."

(Interview. Zeta Club member, Westhill MIND).

A number of respondents felt that their own or others' involvement was a good preparation for paid work. Five people said that their voluntary work in the National Office was valuable in this respect in providing relevant experience.
"...I like it because it gives me a sense of having a place in society, contrasting that with being unemployed. I find it satisfying because I am interested in health problems. I like the structure: come in at nine, go at five..."

(Interview. Volunteer, National MIND).

Several authors describe the value of participation in enabling people to acquire new skills or knowledge (79), but this was not mentioned by many respondents. Some participants described ways in which consumer involvement helped with individuals' rehabilitation, including five National MIND volunteers, who felt that work in Headquarters had helped them to develop skills which could be used in paid work. One day centre member on Eastvale MIND's Executive Committee said that his participation had "broadened my horizons... about what MIND's about and trying to achieve. It opens your eyes to things that you wouldn't normally think about...". Many consumers appeared to benefit both themselves and other people in their Local Association through the use of particular skills. Thus, one Zeta Club member described the satisfaction that she gained from contributing to the running of the club and contrasted this with a previous Local Association, in which she had been treated in a patronising way and not allowed to contribute.

The Chairperson of one Local Association, who had become involved in MIND out of gratitude for the treatment he had received as a psychiatric inpatient, said that he had been able to use his skills as a public speaker (which he had developed as a teacher) to good effect, when representing his Local Association on the Community Health Council and other Committees.
"...I enjoy public speaking and I have a voice which can be heard... I was very active in the professional world... really this is a continuation... I am not the slightest bit deterred if I hold a different view from a committee of fifty..."

(Interview. Chairperson of Local Association with High Consumer Involvement).

There were mixed views about the effects on consumers of taking on responsibility. Whilst some respondents felt that this increased participants' self confidence, others described factors within the individual and/or the organisation which made this difficult. The former included limited self esteem, confidence, ability or motivation, which, it was said, made it hard for some consumers to take on responsibility, make decisions or put across points in meetings. Several respondents, both in MIND and in the three self help groups which were studied, attributed such difficulties in some instances to participants' mental health problems (80), or stated that responsibility caused some consumers excessive stress, which was hard for them to cope with. Some people compared themselves unfavourably with professionals.

"...I'm not educated enough, can't speak. I'm different to social workers. If anyone says anything to me, I argue... I couldn't take it...".

(Interview. Delta Club member, Westhill MIND).
"...I think some of us feel out of our depth in dealing with professionals and feel inarticulate. Some people came along and felt "I can't cope with this"...

(Interview. Officer with consumer experience in a Local Association with High Consumer Involvement).

Lack of confidence made it hard for some participants to cope with meetings.

"...Responsibility may make some people worse. Eg, Jim was very shaky, nervous at an Executive Committee meeting: shaking when reading minutes. At other times, it's good for him."

(Interview. Executive Committee member, Eastvale MIND).

"...At MIND meetings my heart bleeds when [consumers] stutter their way through, or express delusions, and this could be off putting to other people... sometimes it's difficult to... help... and bring them back to the here and now...

(Interview. Westhill MIND staff member)

Taking on responsibility was also said to cause difficulties to members of Depressive Anonymous. Respondents said that people tended to leave this organisation if they were asked to help because this made them feel under pressure.
"...if you wait for someone to volunteer their services, it seems to work better than talking them into it. Other people [in Depressive Anonymous] talk people into doing things, but the person disappears: feels guilty because they can't cope with the responsibility. If someone volunteers, I'll point out they're volunteering... while they feel they can..."

Interview. Officer, Westhill Branch of Depressive Anonymous).

This respondent pointed out that active participation in decision making was not necessarily a good thing for those members who tended to try to cover up their depression, by involving themselves in activities. Participation in Depressive Anonymous might merely perpetuate this tendency.

ORGANISATIONAL FACTORS

Within MIND, several respondents mentioned organisational factors as contributing to the extent to which consumers could cope with responsibility, and as causing them benefits or problems. Several participants commented favourably on the relaxed and informal atmosphere of their centre or club (81), and four volunteers said that they liked National MIND for similar reasons, with one respondent saying that she appreciated the "friendly understanding environment". However, overall, far more problems than benefits to volunteers from organisational factors were reported by National MIND respondents, particularly by staff. These included inaccessibility to consumers and remoteness from them, and organisational complexity: factors which were said to cause
problems to consumers who wished to participate. A lack of opportunities for formal consumer involvement at National level was described by some participants. Views about policy to increase consumer involvement were mixed. Some people, especially National MIND staff, felt that these policies would benefit consumers and facilitate their involvement. Others felt that there was a lack of policies on consumer involvement (82). A few staff members felt that National MIND’s organisational culture made it very difficult for people to "come out", and share their own personal experience of mental health problems. This was said to cause problems to people who wanted to participate in the organisation as consumers (83).

Several National MIND respondents commented that compared with Headquarters, there were more opportunities for consumer involvement in Local Associations, and/or that this was easier to achieve in the latter. Several Eastvale MIND participants felt that open meetings were of value to day centre members (84), and respondents in a number of Local Associations commented that the relaxed, informal atmosphere of various services benefited consumers who wished to participate. An Executive Committee member of Westhill MIND stressed the importance of an organisation which was flexible and responsive to individuals' needs:

"..A client helped with decorating the club premises.. He knew he could [come and go], without people saying "where have you been?.."

(Interview. Executive Committee Member, Westhill MIND).
In contrast, some respondents in Westhill MIND, and in one of the Local Associations with high consumer involvement, said that the complexity of their organisations and of meetings sometimes caused problems for consumers.

"..Of two members who went [to an Executive Committee meeting], one said she felt completely out of it and it was a waste of time. They were made to feel insignificant.. The volunteers had no interest: saw it as an ordeal .. We all knew [serving on the Executive Committee] would make no difference: long winded talk and made to feel insignificant.."

(Interview. Zeta Club Member, Westhill MIND)

"..I think it’s difficult to know how a structure can facilitate consumer involvement.. How can consumers who lack confidence, verbal skills, make their voice heard in a structure requiring confidence and verbal ability?.."

(Interview. Professional Member of Executive Committee, Westhill MIND).

Respondents in Westhill MIND, and in an Association with high consumer involvement, indicated that their organisations' increasing complexity, and accountability to funders, caused difficulties for consumers who wished to participate (85).
"The Committee have a responsibility for the building in legal matters... so they want to know what is going on... Every new project needs ironing out. We don't want to create a bad impression. So things have to be well organised... That works against consumer involvement..."

(Staff Member, Local Association with High Consumer Involvement).

There were few comments about Eastvale MIND's open meetings or Executive Committee meetings causing problems to consumers (86), but in some other Local Associations, and at National level, several respondents commented that the complexity of meetings, their structure, and the jargon used, caused problems to consumers and hindered their participation. Meetings were sometimes said to fail to meet the needs and interests of service users. Eg., one consumer respondent felt that meetings were too rational, with no opportunities to share feelings, and another commented that the subject matter of meetings was often unlikely to interest many consumers.

A few respondents felt that there were particular problems with the language and style of National MIND meetings and literature (87).

"The way things are discussed, the way papers are put together, is off-putting to anyone, not just a consumer..."

"The way people talk and write and... the jargon they use [is a problem]... Our so-called consumer-based leaflets are not written for the Sun readership".

(Interviews, Regional Directors).
Whilst some respondents described ways in which consumer involvement valued participants and provided opportunities for rewarding, responsible roles, others felt the reverse was true. A number of respondents felt that consumers were treated in a patronising or invalidating way, and some National MIND participants felt strongly that volunteers at Headquarters were not valued, and that this was reflected in tasks which were described by a few respondents as "lowly", "unrewarding" and "demeaning". One respondent referred to negative staff attitudes towards volunteers, and another to the latter's low status and absence of staff planning of their work. The nature of volunteers' work was the factor most frequently cited by National MIND staff as causing problems to individual volunteers. Non-volunteer respondents rarely referred to benefits which volunteers obtained from the work itself, as opposed to other benefits. Several respondents commented on what they felt to be the menial nature of the clerical work of the Dock Green MIND volunteers.

"..I think volunteers are used to doing shit work.. They are not allowed to get involved."

"..a feeling by the Union (88) that volunteers are used for very menial tasks.."

(Interviews. Staff members, National MIND).
Several respondents referred to the lack of space which volunteers had for their tasks, and to the lack of a policy for organising and supervising their work, although volunteers themselves did not mention these points in interviews. Four staff members commented that volunteers were exploited by the organisation.

"...They are used for mundane tasks no one is prepared to do..."

"...Their role should be made very clear. They have a job and expertise, but are not paid for it. They should not be made dogsbodies..."

(Interviews. Staff members, National MIND).

One respondent said that the Trade Union to which some staff belonged had expressed "...concern about (volunteers') conditions of work. The Union objects to their not being paid adequately..." (89).

Despite the negative views of some staff, volunteers themselves expressed more satisfaction than dissatisfaction. Thus, two volunteers, not engaged in routine clerical work, said that they found their work boring some of the time, but both also described the satisfaction which they derived from it. One of these respondents said that her work was interesting at times, and the other referred to benefits such as the atmosphere, the people she worked with, and her agreement with MIND's cause. She added:

"...sometimes the work is tedious, but it's good to do mundane work if I feel low. I feel I have achieved something at the end of the day..."
A Dock Green MIND volunteer also indicated that apparently uninteresting work had its advantages, saying that he liked "...doing jobs where I don't have to use my head, so I can think about problems...". This respondent also welcomed the freedom to come and go as he pleased, which, he felt, he would not have in a full time paid job.

Three volunteers referred to their own experiences of being exploited (90), but their feelings about this were mixed. One Dock Green MIND volunteer mentioned both the advantages of his involvement and a feeling that MIND treated him and another volunteer unfairly because the organisation would not pay them bus fares (91). He said that some people had stopped volunteering because of the way they were treated.

"...Bob and a few [other] volunteers ... packed it up because MIND did not treat them right. They felt MIND was mean.."

(Interview. Volunteer, National MIND).

Another volunteer referred both to several satisfactions with his work and to being exploited. He had found the work "intellectually and socially stimulating..." and had been considerably involved in the work of a Department in the National office. His tasks had included writing speeches for a former senior staff member. He felt that his subsequent career had benefited from the experience he had gained, but:
"...looking back I think I was treated shabbily. I feel I was being used. I think they've had three years of unpaid high level work from me. [The former staff member for whom he wrote speeches] gets people to do things for him because of their vulnerability."

(Interview. Volunteer, National MIND).

EMPOWERING CONSUMERS

Some respondents in National MIND saw the nature of the participation of volunteers as diminishing the latter's status, with a failure to give them any power or real responsibility in the organisation. A few respondents felt that this was partly caused by some participants' negative attitudes towards volunteers (92). In contrast, many respondents, particularly at local level, referred to the benefits of consumer involvement in empowering consumers or giving them more choice. In the literature, there is a similarly wide variety of views on whether or not participation truly empowers consumers, or merely serves the needs of officials and supports the status quo. Some authorities make a distinction between "real participation" and "pseudoparticipation" (93). Whilst much of the literature argues that certain types of participation enable power to be shared (94), others state that such involvement fails to change distributions of power (95), is on officials' own terms (96), and supports the status quo (97).

Advantages of participation which have been described include helping consumers to build up solidarity or collective strength (98), offering more choice (99), and enabling individuals to make their needs known to decision makers (100). However, participation has been said to fail to
effect wider policy decisions (101), and some authorities have commented on a tendency for radical, participatory organisations in the U.K. to become traditional, conservative and "depoliticised" (102). Participation has also been described as serving the ends of people in power, e.g., by legitimising existing institutions (103). The failure of consumers to influence policy because of their lack of power, authority or political "clout" has also been referred to (104).

In the present study, some respondents felt that consumer involvement in MIND resulted, or would eventually result, in gains in power or status, but about equal numbers felt that this was limited, or (in the case of some National MIND respondents) that consumer involvement was status-diminishing. Many of the respondents who described potential or actual gains in empowerment were involved in Westhill MIND, but such gains were mentioned by very few Eastvale MIND participants.

"..One Club member was going to change the face of MIND.. I think it did him good getting things off his chest. He was respected for it afterwards."

(Interview. Zeta Club member, Westhill MIND).

"..Tom has got out of the way of seeing himself as a consumer, and Amy has, as well. It's about power: seeing themselves as helper, rather than helped. They've been very keen to be involved in campaigning .. I think it's been very therapeutic."

(Interview. Staff member, Westhill MIND).
A few respondents commented that participation gave consumers a voice and enabled other participants to be aware of their views, and to provide services which were more likely to meet consumers' needs.

"...If consumers have a say in service delivery .. the spin off is that there should be services more geared to the needs of consumers, rather than what professionals think they should be about...

(Interview. Professional member of Executive Committee, Westhill MIND).

"...That they do have a say [is important] - not the downtrodden patients they used to be...

(Interview. Staff member, Westhill MIND).

Some respondents said they had felt powerless when they had received inpatient psychiatric services, and saw their involvement in a Local Association as a means to gain power for themselves and other people with consumer experience. A few respondents had determined to do something to change deplorable mental health services after their own adverse experiences. These participants reported increases in self esteem, and in some instances, decreased powerlessness as a result of their participation (105).

Voluntary organisations which are characterised by solidarity (106) enable people who share a common problem to come together, share power and bring about change. It was partly for these reasons that the American patients' rights movements, and in this country, the Mental
Patients Union and PROMPT (later Campaign Against Psychiatric Oppression (CAPO)) were founded (107). In the present study, members of CAPO described ways in which their involvement in the patients' rights movement helped to increase their feelings of empowerment and awareness of their oppression as psychiatric patients. CAPO respondents felt that it had been difficult to attract a large membership to the British patients' rights movement (108) because of lack of awareness (109) and the fact that it was easier for many psychiatric patients to "play the rules of the game": to accept mental health professionals' definitions of themselves as "mentally ill" (110).

Hal: "You're in their power. If they (i.e., mental health professionals) tell you you're pathetic... you've got to [believe it]."

Gus: When you get better, you say "I was wrong before, couldn't think straight".

Ian: You've got to bluff your way out of it.

Gus: Got to learn the rules of the game.

Hal: A lot of people are angry with things that happen to them, but say "I was ill"... that is... the problem".

(Group Interview with three members of Campaign Against Psychiatric Oppression).
Reference has been made to distinctions between "true" and "false" participation (111), and Chamberlin, in particular, distinguishes between "real alternatives", in which consumers have the power to run, and make all the decisions in mental health services; and those services which are "false alternatives", with mental health professionals apparently interested in participation, but in reality being in ultimate control (112). Whilst many respondents reported what they felt to be "real" increases in consumer involvement, a minority, mainly National MIND staff, questioned the extent to which some participants "really" wanted consumer involvement or were prepared to increase the power of consumers. Many respondents at Headquarters said that staff and Council of Management saw consumer involvement as a priority, and referred to organisational policies to increase this; but a few staff members questioned whether there was a "real" commitment to implement it, or said that the degree of commitment to consumer involvement varied with different participants. Several National MIND respondents said that the existing power of "non-consumer" members of the organisation hindered the development of consumer involvement. A few respondents felt that ulterior motives lay behind the wish to increase it: eg, because participation was "fashionable", or seen to "look good" in the organisation, or increased its credibility (113).

In contrast, other respondents, particularly at local level, felt that consumer involvement facilitated a more egalitarian or democratic organisation. Members of Zeta Club in Westhill MIND commented on the basic equality and lack of distinctions between members. "...I think the Group are quite happy for everyone to be equal ... I find it quite therapeutic" said one club member, whilst the Chairperson of Eastvale...
MIND felt that consumer involvement enabled consumers to mix on more equal terms with professionals and gain more direct access to them. However, some Westhill MIND respondents reported dissatisfaction with the limited involvement of Zeta Club participants in the running of the organisation, and the lack of equality between club members and other participants.

"...Consumers are reluctant to be involved and are intimidated, especially with professionals. I think it's never been resolved in Westhill MIND: a huge gap - an Us and Them feeling .."

(Interview. Staff Member, Westhill MIND).

In contrast, the majority of Eastvale MIND day centre members seemed happier with the Local Association and its Executive Committee. Whilst many of these participants were satisfied with the way in which decisions were made, some felt that day centre members had insufficient say in decision making (114), although three respondents attributed this to participants' reluctance to be involved.

"... the people who are not on any Committees, the general members .. don't get told - have to find out things for themselves. ..People are told "I'm not telling you: there's a notice board up there".."

(Interview. Day Centre Member, Eastvale MIND).

Two respondents who were members of both the day centre and the Executive Committee were concerned that some of their suggestions or decisions were vetoed by other non consumer Executive Committee participants.
"...the only thing I get a bit narked about, is when something I suggest gets thrown out by the Executive Committee ... especially when I have taken great care [over it]. Still, you've got to accept these things."

(Interview. Day Centre and Executive Committee Member, Eastvale MIND).

However, such a view was unusual in Eastvale MIND. Whilst some National MIND staff, and participants in Westhill MIND and in other Local Associations, expressed dissatisfaction with the distribution of power in the organisation, the majority of respondents (including Eastvale MIND day centre members and most other people with consumer experience) appeared to be satisfied with this (115).

**SUMMARY AND CONCLUSION**

This Chapter has reviewed the benefits and problems of consumer involvement to the individual consumer in MIND. Overall, respondents reported more benefits than problems to the individual. There was variation in the extent that consumer involvement was salient to respondents, but the vast majority were in favour of increasing such participation within MIND. Few respondents felt that the organisation should be entirely consumer - run, partly in view of the wide range of needs and interests which it served.
For some respondents, extrinsic rewards of consumer involvement were important, but most participants placed more stress on intrinsic benefits, such as increases in psychological well being, responsibility and empowerment. Gains in self confidence, and feeling valued and of use, were particularly emphasised. Views on the effects on the individual of taking on responsibility varied. Some respondents described resultant increases in self esteem and preparation for taking on other responsibilities. Others outlined problems, such as increased stress which occurred when consumers lacked the confidence or motivation to cope with responsibility.

External factors also resulted in benefits and problems to participating consumers. Benefits included interesting roles and responsibilities and a relaxed, informal atmosphere. Problems could result from demeaning or unrewarding work, and complexity in the organisation and its meetings.

There were mixed views on the extent to which MIND empowered consumers. Whilst some respondents felt that consumer involvement facilitated greater democracy in the organisation, others questioned whether consumers would be given "real" power.

The next Chapter considers the benefits and problems of consumer involvement to other participants in MIND and to the organisation as a whole.
Consideration is given in this Chapter to the benefits and problems of consumer involvement in MIND, with particular reference to consumers and other participants, and to the organisation as a whole. Reference is also made to relevant literature and to the other voluntary organisations studied.

Accounts of the benefits of consumer participation to organisations have referred to perceived improvements in decision making (1), policies and service provision (2). Such improvements have been described as being more likely to meet consumer or public needs (3), and to provide more choice (4). Consumers' expertise, knowledge and skills have been described as of value to organisations which serve people with similar difficulties or circumstances (5). Consumer participation is said to fulfil the needs of professionals or administrators (6), sometimes for ulterior motives such as the legitimisation of institutions or of decisions which have already been made (7). In addition, participation is thought by some to have benefits for the common good (8), and for democracy in general (9). Consumer involvement in mental health services has been described as reducing stigma (10), and improving the public image of mental illness (11).

The literature includes references to a number of problems experienced in organisations as a result of consumer participation. These include the unwillingness of consumers to participate, despite opportunities and
encouragement to do so (12), for reasons such as lack of confidence or skills (13). Difficulties sometimes result from differences in perspective between consumers and others. Thus, consumer participation may be seen as inappropriate, irresponsible or irrelevant (14), unrepresentative of other consumers (15); or resulting in expressed views or actions which do not accord with the opinions, needs or interests of administrators or professionals (16), or which cause them conflict or difficulties (17). Consumer participation has also been described as costly in time (18) and money (19).

Tables 9.1 and 9.2 indicate benefits and problems of consumer involvement to the organisation or to other participants, which were most frequently mentioned by MIND respondents (20).

TABLE 9.1

MOST FREQUENTLY REPORTED BENEFITS OF CONSUMER INVOLVEMENT TO THE ORGANISATION/OTHER PARTICIPANTS

<table>
<thead>
<tr>
<th></th>
<th>Consumers n=9</th>
<th>Other Participants n=6.5</th>
<th>Total n=12.4</th>
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<tr>
<td>Consumer views/ perspectives</td>
<td>7</td>
<td>25</td>
<td>32</td>
</tr>
<tr>
<td>Help/support to other consumers</td>
<td>18</td>
<td>4</td>
<td>22</td>
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<tr>
<td>Skills/abilities</td>
<td>3</td>
<td>8</td>
<td>11</td>
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<tr>
<td>Providing others with interesting activities</td>
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<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Enabling provision of a better service</td>
<td>3</td>
<td>3</td>
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</tbody>
</table>
### Table 9.2

**Most Frequently Reported Problems of Consumer Involvement to the Organisation/Other Participants**

<table>
<thead>
<tr>
<th>Problem Description</th>
<th>Consumers</th>
<th>Participants</th>
<th>Total</th>
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<tr>
<td>Consumer views/perspectives</td>
<td>8</td>
<td>17</td>
<td>25</td>
</tr>
<tr>
<td>Problems from the participation of particular consumers (e.g., because of personality/mental illness)</td>
<td>9</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>Difficulty taking on responsibility/making decisions</td>
<td>6</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>Lack of real changes of power in the organisation</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

Many MIND respondents referred to the consumer perspective and the effect that consumer involvement had on other participants, particularly other consumers. Mixed views were expressed about both these areas, with participants, particularly non-consumers, referring both to the value to the organisation of consumers’ views and experiences, and problems which resulted, or could result, from differences of opinion between consumers and other participants. The help and support which consumers gave to other people with similar problems was emphasised at local level, but there was also mention of difficulties to others caused by the participation of particular consumers. Such difficulties were often said to be caused by participants' mental health problems or personality traits such as authoritarianism. The value of mutual aid (21), and both benefits and problems of the consumer perspective, are mentioned in much of the literature, but less appears to have been written about difficulties resulting from the participation of consumers with mental health problems, or personality traits which cause problems for others.
Whilst some respondents described consumers' skills and abilities which benefited MIND and helped the organisation provide or press for better services, about equal numbers referred to the difficulties that consumers had in taking on responsibility and/or the lack of real changes in power which resulted from consumer involvement. Other benefits and problems to the organisation, described in the literature, were rarely or never mentioned by respondents.

The main benefits and problems of consumer involvement to other participants, and to the organisation, will now be considered in turn, in relation, in particular, to mutual support, responsibility and decision making, and consumer views.

**MUTUAL SUPPORT**

Several authorities have described the benefits of mutual aid or self help (22), with gains accruing both from receiving and from giving help (23). These include satisfactions from helping others (24), from giving as well as receiving (25), and from the individual taking on responsibility for her/his problems (26). Such benefits were described by a number of MIND respondents, who reported benefits both to the individual and to other people. Both the literature and the present study suggest that benefits to self and others in mutual aid seem inextricably linked. They will therefore be described together.

Several respondents described the benefits which they or other participants derived from helping others.
"... People who've been on the receiving end of services can get a lot back from channelling their energies in giving something back. The self help ethos is an alternative to treatment..."

(Interview. Professional Executive Committee Member, Westhill MIND.)

"... I enjoy [helping] others. It makes me happy, I've found my inner strength if I can help people... It gives me inspiration to come out of myself... My... goal is to help others... I get a lot from it... without that I would have nothing..."

(Interview. Member with consumer experience, Local Association with high Consumer Involvement).

Other respondents described the friends they had made through the Local Association. Often members met each other outside the Club or Centre, and this was particularly true of Dock Green MIND volunteers who worked in the National Office and the members of Delta Club in Westhill MIND, many of whom lived in a local housing estate. Dock Green MIND volunteers often worked and took their breaks together, and valued their friendship and their shared experiences.

"... We're all the best of friends... We go to the Club... we all used to go to a Day Centre..."

(Interview. Volunteer, National MIND).
In the Local Associations with high consumer involvement, and in the other voluntary organisations which were studied, several respondents said that they felt they could give to others because of their own experiences of mental health problems or services (27). Thus, two Chairpersons of Local Associations, one of whom had founded his Association, said they had become involved because they were grateful for the treatment they had received, and wanted to give something in return. Members of Campaign Against Psychiatric Oppression and an Officer in one Local Association indicated that they derived benefit from helping others who, like themselves, had suffered oppressive experiences in psychiatric hospitals.

".. I was the main instigator [of consumer involvement] because of my own experience, pushing it more than other members. Now I've got allies...".

(Interview. Secretary of a Local Association with high consumer involvement)

This respondent described the value she had derived from becoming empowered through her attempts both to change bad conditions in local mental health services and to enable other consumers to become more empowered. Another respondent also experienced less helplessness when she joined a Local Association. In addition to experiencing mental health problems herself, she was the mother of a young man with schizophrenia who had killed himself.
"...our son ... need not have died if things had been available. We [husband and herself] feel we'd like to do something because there's such a lot missing. My Doctor said "You mustn't be involved. It will not do any good." I think that is wrong .. because if everyone took that attitude, nothing would be done..".

(Interview. Secretary, Local Association with high consumer involvement).

Much literature on self help groups describes the benefit which people derive from sharing experiences with others who have similar problems (28). ".. Those who have experienced [traumatic] situations often feel that .. support is most meaningful and helpful when it comes from others who have been through it .." (29).

A similar view was expressed in the literature of the three self help groups which were studied.

".. Everyone involved in Depressives Anonymous is either a present or a past sufferer from depression, for our fundamental belief is that depressives can help themselves and each other by the very fact of their shared affliction.." (30).

The benefits of helping others in similar circumstances were described by several respondents, some of whom referred to the value of their own experience in understanding people who came to their Local Association for help.
"...People generally [in the respondent's Local Association] are for caring for each other. People who've had mental illness seem more sensitive to others suffering the same things...".

(Interview. Lay Chairperson of a Local Association with high consumer involvement).

"... I am better now, but I do remember how terribly unhappy I was when ill, and it's that that makes me hold back from getting faster [in meetings]..."

(Interview. Chairperson with consumer experience, Local Association with high consumer involvement..)

"... I think my experience has made me a better person. I can feel for people more, I can feel real pain for them. Because you know what they're going through .. and you understand them .. because you've had firsthand experience .."

(Interview. Secretary with consumer experience, Local Association with high consumer involvement).

Another Officer of a Local Association, who ran a telephone counselling service from his home, said that callers sometimes asked if he had himself experienced mental illness, and were more willing to talk to him when he replied that he had:
".. If you’ve experienced paranoia, you know what it’s like. If you’ve seen and heard things which are not there .. you know what they’re going through. A number of people [in the respondent’s Local Association] have experienced it: our attitude is more realistic because of it. ..".

(Interview. Chairperson of a Local Association with high consumer involvement.)

In the literature, a frequently reported problem of Self Help Groups is a lack of active participation of many members, which sometimes means that a few participants give most of the support and take on much of the responsibility for the Group (31). In the present study, this was said to be a problem in Depressive Anonymous (32), but within MIND, few concerns were expressed about any lack of consumers being involved in helping others. However, a few respondents said that the attitudes of some participants made it difficult for consumers to receive the support that they needed. One respondent said she felt that Eastvale MIND’s Day Centre failed to attract certain people with particular problems or with a social class background which was different to that of most members. A member of Westhill MIND’s Zeta Club commented:

".. It’s very cliquey. People talk to the same people every week. I’d like to talk to more ..".

(Interview. Zeta Club Member, Westhill MIND).
In the literature, there are references both to positive and negative attitudes of professionals and administrators towards consumers (33). In some instances, the attitudes and practices of people in authority have facilitated consumer involvement, and this has been the case in some patient participation groups in General Practice (34), Self Help Groups (35), and certain mental health services (36). A "non dominant" professional approach has been found to be helpful in facilitating consumer involvement in studies by Fowler (37) by Richardson and Bray (38), and in the present study (39). Fowler refers to Wilding's idea of a "partnership model" in which professionals share information with consumers and involve them in decision making (40). However some writers have described "Mentalism": prejudiced attitudes towards, and stereotyped ideas about, people with mental health problems (41).

Many accounts by consumers and by social scientists, including antipsychiatrists, have highlighted mental health workers' negative attitudes to users of psychiatric services. Such attitudes have often resulted in a failure to provide service users with sufficient choice, or to consider their wishes (42), with the imposition of institutionalised regimes which fail to take account of individuals' wishes or their abilities to make decisions for themselves (43). In many psychiatric hospitals, patients have been dehumanised, with much of their thoughts and behaviour being wrongly attributed to mental illness, and their ideas and suggestions not taken seriously (44). The therapeutic community movement was inspired, in part, by a wish to break down unnecessary barriers
between residents and staff, and enable the former to have autonomy, express their views and be involved in decision making and responsibility (45). However, Chamberlin has criticised therapeutic communities for failing to change staff attitudes or to result in "real" distributions of power (46).

Several writers state that the frequent failure of consumer involvement to result in shifts of power (47) is caused by the domination of people in positions of authority and by their attitudes (48). Boaden et al conclude that "... elite domination of public services is universal." (49). Hughes states that "participation is critically dependent upon the attitudes of Government", and argues that in many countries the political and cultural environment is not conducive to participation (50). Colom, a former consumer of mental health services, states that:

"... the greatest deterrent to client participation in Community Mental Health is the attitude of professionals who assume knowledge of what is best for the individual, rather than allow the client responsibility for her/his own life." (51).

Several respondents said that the attitudes of MIND participants were an important component in either raising consumers' self esteem and facilitating consumer involvement; or in causing them problems and hindering their participation. Overall, more problems than benefits from participants' attitudes were reported by respondents. In particular, several people felt that the attitudes of mental health professionals, consumers and National MIND staff were especially crucial (52).
Two respondents contrasted their present satisfaction with their considerable participation in their Local Association with past condescending attitudes of mental health professionals, who had prevented them from being as involved in Association affairs as they would have wished. Respondents in Westhill MIND and in several of the Local Associations with high consumer involvement felt that the domination of mental health professionals or other participants made it hard for consumers to be involved (53), with a few respondents highlighting particular difficulties in this respect.

"...consumers are reluctant to be involved and are intimidated, especially with professionals. I think it's never been resolved in Westhill MIND. There's a huge gap: an Us and Them feeling, ."

(Interview. Westhill MIND staff member.)

Several respondents, particularly those in Eastvale MIND, commented that project members themselves often made it difficult for other people with consumer experience to participate. The attitudes of some Day Centre members in positions of responsibility were said to sometimes cause problems for other members. Although most of the latter expressed considerable satisfaction with the Centre, and the atmosphere was often observed to be relaxed and friendly, many respondents expressed misgivings about the aggressive and rude attitudes and behaviour of some participants. This was sometimes noticed during participant observation. One respondent said of another member who was on the Executive Committee:
"... He goes too far with his mouth, which I want something done about. So do a few others. He lets it go to his head. He thinks he's running the place with his mouth."

(Interview. Day Centre Member, Eastvale MIND)

A lay Executive Committee member commented:

"... [A named Steward's] attitude to new people may result in people not coming again. The Steward .. has to represent the Centre ..".

A few respondents in other Local Associations described isolation from other consumers who were said to fail to support them in their own attempts to participate. Thus, one individual said that he disagreed with the radical perspectives of other people with consumer experience in his Local Association, and indicated that he felt isolated from them. One Zeta Club participant in Westhill MIND felt apart from other members because no-one agreed with his attempts to formalise decision making. Other people's comments suggested that this participant was not popular. In another Local Association, one respondent with consumer experience said that other participants' attitudes towards him made his involvement particularly difficult. He described other people sniggering at him in meetings, or not offering to help him with work.

"...When I complain about it, it's seen as shit stirring .. I felt put on .. a lot of people who stand around doing nothing."

(Interview. Consumer Member of Local Association with high consumer involvement)
As in other societal groups, members whose views differed markedly from others' sometimes seemed to find it hard to get them accepted (54).

".. the only one .. that annoyed people .. the only one who wanted to take over was May. Her ideas were so crackpot, we said .."silly idea", ignored it, and let it die down.."

(Interview. Delta Club member, Westhill MIND).

Some National and Regional MIND staff referred to "Mentalism": prejudiced attitudes towards people with mental health problems, which they felt some MIND participants possessed. In particular, six National MIND staff described, often strongly, negative attitudes of some staff towards volunteers, which they felt made it hard for the latter to participate. Such attitudes included failure to treat volunteers as equals or to offer them sufficient support, and the allocation of tasks which diminished, rather than enhanced, volunteers' status (55).

The problems encountered by a few consumers who were unsupported in their attempts to take on responsibility have been described. The next Section examines the effects on the organisation of consumers' involvement in responsibility.
CONSUMERS WHO TAKE RESPONSIBILITY IN THE ORGANISATION

In outlining the effects of consumer involvement on the organisation, respondents described both benefits and problems in relation to individuals’ skills and their ability and motivation to take on responsibility.

Data from interviews suggests that some Local Associations owed their foundation, continued existence and activities, to the efforts and skills of people with experience as consumers (or in one case, of relatives.) (56). Many of these respondents facilitated the involvement of consumers and/or relatives, the provision of mutual support, and in a few cases, the provision of services. The contribution of Day Centre and Club participants to the work of Eastvale and Westhill Local Associations has already been described (57). Data from participant observation and interviewing suggest that it would have been difficult to have run many Local Association projects without the considerable contribution which users made towards their running and the provision of a mutually supportive environment. An Executive Committee Officer of Eastvale MIND commented that "..high involvement of users [means that] decisions are readily accepted and implemented.." (58) whilst a Day Centre member remarked that fellow users had "..fitted in nicely, and that has helped the Centre to run smoothly.." (59).

Some respondents referred to particular gifts or abilities which consumers gave to the National Office or to their Local Associations. Four National staff members described the value of particular volunteers’ abilities, skills and effort. One respondent said that some consumers had helped or ".. donated something to the organisation, financially, or in terms of good will .." (60).
Volunteers' work was described as being of value, and according to one staff member, saved MIND money. A few National MIND respondents felt that the organisation would benefit from the employment of people with consumer experience, who could make a valuable contribution from their knowledge of mental health problems and services. However, one Regional Director stated that ability to do the job would also be important, whilst another respondent commented:

".. I don't positively discriminate. We're under-resourced, so it's difficult to carry passengers. People need to be mentally healthy to work here with the stress. If MIND wants positive discrimination, they have to free staff to give support. We're overstretched."

(Interview. National MIND Staff Member).

At local level, the valued contribution which consumers could make to Westhill MIND was acknowledged by Executive Committee members, who said they were keen to increase consumer involvement in the running of the organisation.

".. There are some individuals who could make a valuable contribution, partly because they're excellent organisers, and have much to contribute."

(Interview. Executive Committee Officer, Westhill MIND).

In Eastvale MIND some respondents described benefits to the Local Association from Day Centre members' fund raising efforts (61), whilst three Westhill participants commented that increases in consumer
involvement could be of value to the Local Association in facilitating campaigning and enhancing its influence on policies and service provision.

"... [Two Club members with consumer experience] are very keen to be involved in campaigning and are aware about issues ... very useful ... essential to the Local Association that they've been involved . . .".

(Interview. Staff Member, Westhill MIND) (62).

One Westhill MIND Executive Committee member felt that more consumer involvement would enhance the Local Association's credibility:

"... Any organisation that has genuine grassroots [involvement] is . . . strong. ... There is more likelihood that the Local Association will reach its objectives if it has a good grassroots foundation . . .".

(Interview. Executive Committee Member, Westhill MIND).

Some respondents referred to problems which resulted from consumers' unwillingness or difficulty in taking on responsibility, which was reported to often be related to individuals' mental health problems. Low levels of consumer involvement in organisations which have encouraged this have been reported in the literature (63), with, in some cases, resultant excessive demands on a few individuals, on whom the burden of responsibility has fallen (64).
Some Executive Committee participants in both Eastvale MIND and Westhill MIND said that consumers did not taken up offers of opportunities to be involved in the Associations' Committees. Thus, although Zeta Club members had been invited to attend, no one did so (65), and in Eastvale MIND, participants who were members of both the Day Centre and the Executive Committee, often failed to attend meetings of the latter. Problems such as consumers' lack of attendance at meetings, and their difficulty in taking on responsibility for things they had promised to do were also described by some participants in Local Associations with high consumer involvement. Such problems were sometimes attributed to participants' mental health problems (66).

"...People want to do things, but are reluctant to take on specific responsibility. They want an anchor man to fall back on. They are reluctant to fund raise without a staff member...[fund raising] wouldn't happen [without staff]."

"... Immediately you put pressure on, they leave... So obviously, we have to rely on good sound individual volunteers who don't have problems..."

(Interviews. Officers of Local Associations with high consumer involvement).

The second respondent quoted above commented that once people had gone through mental health problems, they tended to "distance themselves from mental illness", and lessened their involvement in the Local Association.
A number of respondents described potential or actual problems to the organisation which resulted from consumers' difficulties in taking on responsibility. A member of Delta Club in Westhill MIND said:

"...Well, I don't think they do take on responsibility. They just go there and expect others to do it for them ... [and] tag along with whatever is suggested. I don't think. May wants responsibility, but she does it because she's always done it. She said the other week: "... I don't know why you all rely on me: you all see me being in charge ..." I don't think they want responsibility..."

(Interview. Delta Club Member, Westhill MIND).

An Officer of Eastvale MIND said that consumer involvement sometimes caused problems of confidentiality. "...A problem of saying things that are confidential which we might not want one member to know about another..." (67). Another Officer in this Association commented that consumer involvement in the Committee could cause problems, both for the individual consumer and for other day centre members. Eg, sometimes the latter asked their Executive Committee representatives to effect decisions with which other Executive Committee participants did not agree. "...Because decisions are often a compromise ... they've then got to answer to ... their friends when the decisions have not gone as [they expected]..." (68).

Problems were also mentioned in both Eastvale MIND and Westhill MIND, but not in Local Associations with high consumer involvement, of Day Centre and Club members sometimes making important decisions without consulting
the Executive Committee. A Westhill MIND Executive Committee member described decisions being made in a Volunteers' Group (many of whose members were Club participants) to which the Executive Committee were denied access:

"... the Volunteers' Group is closed, and no one knows what goes on... What access or control would the Executive Committee have if Groups were formed under the auspices of MIND [which] became more... consumer - political? [Staff]... do not have access to meetings. Where does that leave the Executive Committee in terms of management and control?..."

(Interview. Professional Executive Committee Officer, Westhill MIND).

An Eastvale MIND Officer said that he did not always agree with the decisions of Day Centre members, who did not always sufficiently consult with the Executive Committee:

"... Day Centre users are not always equipped to [deal with] the nuances of an argument, so things are not always carried to [the Executive Committee], which I think is a risk worth taking because there are more advantages [in consumer involvement]..."

(Interview. Executive Committee Officer, Eastvale MIND).

Several respondents, including those in Local Associations with high consumer involvement, referred to some participants' difficulty in taking on responsibility because of their mental health problems:
"... People can be so ill that they can't give to others and hang on to survival. It's not so good when several people are ill. Self help has to be reciprocal. When people are encased in themselves, instead of a good feeling being built up, it can be abrasive. Dan tends to be aggressive, verbally when ill, and shouts in meetings."

(Interview. Professional Executive Committee member, Eastvale MIND).

"... There's a lack of consistency. Sometimes they're there, sometimes not. Sometimes keen, sometimes not. The organisation has to run round them, rather than vice versa. Members [participate] depending on their mental state and how far they want to be involved. You can't rely on them. How much responsibility a Day Centre member can take depends on their illness. That's why it's essential to have a core of stable people."

(Interview. Lay Executive Committee member, Eastvale MIND).

A number of other respondents commented that whether people with consumer experience should serve on Committees depended on their ability to cope with responsibility, which in turn was often said to depend on the extent of mental health problems. A few respondents commented that ability to cope effectively in meetings was of more importance than consumer experience.
".. I think it's generally accepted that if you're going to elect a Committee, there should be people capable of doing work on that Committee, and serving the Association properly.. One of the characteristics of mental illness is unreliable and abnormal behaviour patterns so [in my Local Association], people are prevented, in my view rightly,.. from taking positions which they are not .. capable of..

(Interview. Chairperson with consumer experience of a Local Association with high consumer involvement).

In contrast to this view, a small number of participants felt that the running of the organisation and the structure of meetings should take account of the needs of consumers (69).

Consumers were seen as having particular difficulty in taking on responsibility in the Westhill branch of the National Schizophrenia Fellowship (70), where respondents felt that increases in the participation of "sufferers" (71) would be seen as a problem, as they would be unable to support relatives or undertake other responsibilities.

"..I don't think they could participate a lot in the organisation. They can't make decisions, can't cope with stress. They have difficulty in deciding to get up and wash..".

(Interview. Westhill branch Committee Member, National Schizophrenia Fellowship).
"..They're subject to relapse .. and the job [of Committee member] is too important to be given to them without careful consideration .. they are not good on the phone or at putting people at ease .. the work is too important to be left to people who are less than reliable..".

(Interview. Westhill branch Committee Member and former "Sufferer", National Schizophrenia Fellowship).

Reference has already been made to the lack of participation of many members of Self Help Groups (72). This had proved a problem in Depressives Anonymous, where, according to respondents, only a few people were prepared to serve on the National Committee or its sub-committees. Two respondents attributed this, in part, to members' depression. New members sometimes gladly undertook responsibility, but had, in certain instances, left the organisation when their depression had returned, or become worse and they felt unable to cope.

Respondents elsewhere described difficulties caused to others and to the organisation as a whole from consumers' disruptive or aggressive behaviour. Two people said that some members' hypomanic episodes caused problems (usually slight) to the Manic Depression Fellowship.

"..The problems are not depression, but when members are high, and want to start things, and sometimes find it difficult to stop. If we were re-writing the Constitution, we would probably say the Treasurer
should be a non-sufferer because one of the features of mania is a fantastic desire to spend money.."

(Interview. Committee Member, Local Group of Manic Depression Fellowship).

Other problems resulting from hypomania were mentioned by respondents, including the putting forward of an impractical proposal, writing large numbers of letters inappropriately, and personality clashes. A relative commented that sometimes sufferers:

"..become very rampant, disrespectful to the Chairman and won't submit. But if we can't live with them, Society can't. One does not want to control, but ensure that the organisation runs smoothly.."

(Interview. Committee Member, Local Group of Manic Depression Fellowship) (73).

**BENEFITS AND PROBLEMS OF THE CONSUMER PERSPECTIVE**

The literature on Participation refers to both benefits and problems of the consumer perspective. The value to individual consumers of opportunities for communication, including discussion of problems and expression of views have been described (74). Perceived benefits to the organisation from consumer perspectives and experience include improvements in decision making (75) and service provision (76). In particular, consumer involvement has been described as leading to more effective management (77), the facilitation of innovation (78), offering
more choice (79) meeting consumers' needs and wishes (80) and opportunities to determine policies (81). Participation of people with mental health problems has been said to improve the public image of people with mental illness (82). Several recent studies have stressed the importance of considering consumer views as a basis for making changes in Health and Social Services (83), although research by the National Association of Health Authorities found that few District Health Authorities involved consumers in the planning process (84).

Perceived problems of consumer views and perspectives include conflict with those of others, such as professionals and other people in authority (85), and the contentiousness and discomfort which may result (86). The difficulty of different participants (including consumers) having opposing needs and interests has also been described (87), as have the problems of consumers viewing issues in a biased way (88), wanting things which others judge not to be in their best interests (89), and of making contributions which are thought by others to be inappropriate, irrelevant or irresponsible (90). Differences in views about the purpose of Participation is also said to be, at times, a problem (91).

In considering the benefits and problems of consumer views and perspectives within MIND, it should be remembered that, unlike the other voluntary organisations which were studied, MIND has always served a wide range of professional and public, as well as consumer needs and interests, and has had a broad membership of interested mental health professionals and lay people, as well as people with experience as consumers and their relatives (92). Given the wide range of interests served by MIND, and its diverse participants, it is perhaps not surprising that the majority of
respondents at National, Regional and Local levels felt that the organisation should not be entirely consumer-run (93). Only four out of thirty three National respondents expressed unequivocal agreement with this, and several participants pointed out that it would be inappropriate, because the organisation did not exist solely to serve consumer interests. In Eastvale MIND and Westhill MIND, most respondents gave a similar response in relation to their Local Association (94).

Some respondents were asked to what extent they thought National MIND served professional interests, and their views on the extent to which this complemented or conflicted with the serving of consumer interests (95). There was a variety of views, the most common being that there was a conflict of interests (96). Several respondents referred to the education, training and information which MIND gave professionals, but a psychiatrist on the Council of Management, whilst acknowledging this, commented with concern:

"...MIND definitely sees the need to tip the balance of power away from the professional to the actual consumers .. There is always going to be questioning of professional standards and attitudes."

(Interview. Psychiatrist Member of Council of Management, National MIND).

One Assistant Director felt that it was important to maintain a balance between the interests of professionals and consumers:
"...I think it could [conflict]. I'm not sure whether in practice it does ... If we are seen to be in the pockets of professionals, we'll be less interesting to consumers ... If we are seen to be an exclusively consumer voice, professionals will either dismiss us or be less interested in our work ... I think there has to be a balance between the two. Probably the balance is now too much professional..

(Interview. Assistant Director, National MIND).

Whilst three respondents felt that the serving of professional and consumer interests complemented each other, others pointed to potential or actual conflicts:

"... Ultimately, there is a conflict and we can serve both effectively if we are clear where our priority lies. MIND is a patients' organisation. This implies [liaising] (97) with professionals ... but loyalty [to this] should never take precedence over consumers..

(Interview. Assistant Director, National MIND).

One professional member of the Council of Management felt that possible conflict was "...not necessarily a bad thing ... Council of Management are too much on the professional side ..." (98). In contrast, two respondents felt that MIND was over-critical of psychiatrists:

"... MIND knocks the professionals so hard, especially the psychiatrist, that it is counter-productive. It gets MIND written off as a crack pot organisation. It goes too far. It's very hard to keep the balance..

(Interview. Psychiatrist Member of Council of Management).
The foregoing account has been given in order to place consumer views and perspectives in the context of the different interests served by MIND, and its wide membership. The benefits and problems of the consumer view will now be examined.

Overall, amongst MIND participants, more benefits than problems in this respect were described. Some respondents referred to the value of giving consumers a voice. E.g., members of the Training and Education Department of National MIND emphasised the benefits of facilitating this in educational sessions run for mental health professionals, and in the MIND Annual Conferences (99). These respondents stressed the value, both to individual users of services who benefited from the opportunity to express a viewpoint, and to mental health professionals who had the opportunity to listen to a variety of consumer views, often for the first time, in an educational or conference forum.

Some Eastvale MIND respondents commented on the importance of opportunities for Day Centre members to express their views, e.g., in open meetings (100). Some Westhill MIND respondents also commented on the importance of giving consumers a voice:

"...[If consumers] have a say in service delivery .. the spin off is that there should be services more geared to the needs of consumers, rather than what professionals think they should be about."

(Interview. Executive Committee Member, Westhill MIND).
"...[It is important] that they do have a say, not the downtrodden patients they used to be..."

(Interview. Staff Member, Westhill MIND).

A few members of the Westhill MIND Clubs emphasised the essential equality of all members as a value:

"... the sort of thing like our [recent] trip to [a local tourist centre] should be easy-going with no leaders. We should continue that policy where everyone has a say...".

(Interview. Zeta Club Member, Westhill MIND).

Several respondents at National, Regional and Local levels described the value of consumer experiences, views and perspectives to the organisation. A number of National MIND participants commented that the Consumer View enabled other participants, particularly staff, to keep in touch with service users' perceptions, feelings and experience of services. One respondent saw this as being especially useful to National MIND Departments which were not directly in touch with consumers; and other participants referred to the credibility which the consumer perspective gave the organisation, and stated that it enabled MIND to ensure that its work was relevant.

"...It's very good for us to be in close touch with individuals' experience. ... It informs us in the way we develop our ideas..."

(Interview. Assistant Director, National MIND).
"It's just unbelievably important to have people as part of us who use the service and have firsthand experience. Properly channelled, it will make sure we're relevant."

(Interview. Assistant Director, National MIND).

"I think it's good to be reminded of consumer reaction: what it's like to be thrown out of hospitals onto the streets, and be prepared to change our minds."

(Interview. Regional Director).

The consumer perspective was also said to be of value in informing the work of some Local Associations, and this was especially emphasised by Westhill MIND participants, some of whom felt that it was difficult to make informed decisions about mental health services without an adequate knowledge of consumer views.

"You have to have a hot line to the people who use services before you can say ECT or drugs are bad. It gives a more balanced view. Involving people who've experienced mental illness gives people a sense of reality and helps them to keep in touch with what it's like and [gives] a better idea of need being unmet."

(Interview. Professional Member of Executive Committee Westhill MIND).
".. I think [consumer involvement] could [help us] understand the needs of people MIND is supposed to serve in terms of services.. With campaigning, consumers are much more in tune with problems with housing .. We can be distanced from those problems and [with consumer views], we can be in touch with them more.."

(Interview. Zeta Club Member, Westhill MIND).

Another Westhill MIND Club member questioned how far professionals could understand mental health problems.

"..If they haven't experienced anything like it, how can they tell how people are? If I'd not gone through what I've gone through, I'd never have believed it.."

(Interview. Delta Club Member, Westhill MIND).

Some respondents felt that consumer involvement enabled consumers' needs to be met more effectively, and led to the sharing of good ideas and better representation of consumers' views, which could then be taken into account by the organisation. In contrast, other respondents, especially National MIND staff, felt that there was a lack of direct representation of consumer views (101). The lack of communication between Westhill MIND Executive Committee and Club members, and the wish of participants to increase this, has already been described (102). One Eastvale MIND
Executive Committee member commented that consumers on the Committee failed to pass on information to other Day Centre members because they had not "taken it all in" (103). Another member of this Executive Committee felt that there was a danger of Day Centre members' views being ignored. Whilst most Zeta Club respondents expressed satisfaction with their involvement, two participants felt that there was a lack of acceptance or enthusiasm for their ideas.

"... The trouble with [Westhill] MIND, is it encourages negative thinking. Nothing is done to iron things out and raising points... has been suppressed by volunteers... Eve's a killjoy, says it doesn't sound good... about... my ideas..."

(Interview. Zeta Club Member, Westhill MIND).

Whilst most respondents who commented on consumer views and experiences felt that they benefited the organisation, a smaller number of participants referred to problems from the consumer perspective. A few participants felt that consumers' views were sometimes biased or subjective.

"... I... have wider experience dealing with many people, whereas Joe Consumer will have his own experience. I don't say my experience is any better. You need [both] subjective... [and] objective views..."

(Interview. Professional Member, Council of Management, National MIND).
Several respondents commented that the narrowness of the consumer view could be a problem.

"...Consumers might not be concerned with issues beyond... [their personal experience]. To go from discrete personal experience to [broader] issues is difficult...".

(Interview. Professional Member of Executive Committee, Westhill MIND).

"We could get [consumers] with a subjective view who can't see other views or... who are immersed in a problem... can't see objectively what they should be doing just as professionals can only see things from one point of view... [Consumers should have] an ability to stand outside a problem and see it in greater perspective..."

(Interview. Executive Committee Officer Westhill MIND)

A staff member in a Local Association with high consumer involvement felt that sometimes consumers' needs interfered with their ability to help others. Several respondents referred to divergences of opinion between consumers and other participants. Thus, two Council of Management members expressed concern about a "Declaration of Intent", which had been drawn up by a group of people, most of them with consumer experience, at the 1985 World Federation for Mental Health Congress, which was largely organised by MIND (104). The Declaration had, among other things, denied the
existence of mental illness, and called for the abolition of all compulsory psychiatric admissions and treatment. One Council of Management member commented that the credibility of this Declaration could be questioned, whilst another expressed concern that it did not represent the views of the majority of consumers. Some Council of Management members had expressed concern about whether the Declaration represented MIND's standpoint. The National Director said that this was for participants to decide, but that, in any event, it was important that the organisation enabled consumers to share their views (105).

Differences in views between people with consumer experience and other participants at local level have already been referred to (106). Whilst some respondents at different levels of MIND expressed concern about these differences and disagreements, others saw this as healthy or unproblematic:

"...I don't think consumer involvement has caused any problem [to the organisation]. I imagine at local .. and possibly, at National level, consumers might say something that was not MIND policy or [that other participants] disagreed with, or say something [inappropriate]. One or two meetings have been confusing because of odd or divergent consumer views .. but I would not necessarily see that as a problem."

(Interview. National Director).

Two Westhill MIND respondents said they anticipated an increase in differences of opinion between consumers and other participants, but a staff member saw this as potentially creative. She felt that with increases of consumer involvement in Westhill MIND:
"... there could be more conflict of interest .. but I'd see these as creative difficulties. It would be disappointing if there were not conflicts and difficulties. I'd actually expect them ..".

(Interview. Staff Member, Westhill MIND).

Respondents, particularly at local level, described the effects of mental health problems on some participants' views or behaviour, and their consequences for that individual or for the organisation. Many participants felt that previous experience of mental health problems enabled the individual to understand others in similar circumstances, and provided a valuable perspective. However, difficulties arising from the consumer view were also described. These included problems of bias and narrowness, and difficulty in taking a wider perspective. Problems to others resulting from people's mental health problems, eg. difficulty in taking on responsibility or behaviour which others found aggressive or otherwise unpleasant have been previously described (107).

REPRESENTATIVENESS

Finally, some respondents commented on Representativeness: the extent to which participating consumers reflect the views of other users of mental health services. The issue of Representativeness has been addressed in much of the literature on Participation. The term refers to the extent to which particular consumers, especially those acting as spokespersons, voice the views of other consumers whom they claim to represent (108). Several researchers have found that, in the UK and USA, consumer
representatives tend to be unrepresentative of the populations whose interests they purport to serve, tending to be white, middle class and middle aged (109). This has been found in a variety of organisations, including Community Health Councils (110), patient participation groups in general practice (111), community action groups (112) and children's education (113).

In the present study, a number of respondents described problems concerning Representativeness in relation to consumer involvement. In National MIND, the lack of representation on Council of Management, of consumers and of people from black and ethnic minorities, was seen as a problem by several National MIND staff and Council of Management members. In addition, some staff felt that National MIND should provide more employment opportunities for consumers (114). Some respondents described the domination of professionals at National or Local levels of the organisation.

"... Council of Management is not representative of people we're meant to represent: low representation of women and consumers. It's very powerful, but open to accusations that it is white, male dominated."

(Interview. Staff Member, National MIND).

During the period of fieldwork, the system of nomination onto the Council of Management, with new members being proposed by those currently serving, was said to hinder consumer involvement. A new electoral system to ensure better representation of consumers and other participants came into operation in 1986 (115).
Problems concerning consumer representativeness were also mentioned by a few respondents in Local Associations, although overall, this was not often referred to as a problem at this level of the organisation.

"..the problem (is) how to get representativeness of all views.. represent all consumers."  

"..A MIND Group might have a different view to other consumers [i.e. those who are not MIND members] and then there's the dilemma .. Is MIND imposing its views on consumers?.."

(Interviews. Participants in Local Associations with high consumer involvement).

A few respondents indicated that certain factors could affect the type of consumers who were attracted to MIND, which in turn could have consequences for the representativeness of consumers who participated in the organisation. These factors included the accessibility of MIND to consumers and of its meetings and literature (116).

**SUMMARY AND CONCLUSION**

This Chapter has examined the benefits and problems of consumer involvement, mainly to the organisation as a whole, and to other members, besides the participating consumer.
Many respondents described the value of giving and receiving mutual support, and of consumer experience in helping other people. The attitude of other participants was seen as crucial to the success of consumer involvement. Both positive and negative attitudes were described. In some instances, participants' mental health problems were said to result in aggressive or otherwise unpleasant behaviour which caused difficulties to other participants.

Some Local Associations with high consumer involvement owed their founding or continued existence, and much of their work, to the active participation of consumers, and many respondents commented on particular skills and abilities which consumers contributed to MIND. Problems to others because of consumers' difficulties in taking on responsibility were also described, and were often attributed to participants' lack of confidence or skills and/or mental health problems.

Many respondents described the value of consumer views and perspectives, particularly in ensuring that the organisation's work was relevant and meeting consumers' needs. Some conflicts and differences between the views of consumers and other participants were described, but some respondents did not feel that this constituted a problem. Others felt that problems could result from consumer views being biased or narrow, and concern was also expressed about the representativeness of consumer views.

The next five chapters examine factors which facilitated or hindered consumer involvement.
The next four chapters examine factors which facilitated and hindered consumer involvement in MIND, with reference to other voluntary organisations studied, and to relevant literature. After a general introduction, a number of specific areas will be considered in detail:

a) the role of professional, consumer and lay participants, and their power in the organisation (chapters 10 and 11);

b) aspects of organisational structure, aims, meetings and policies (chapter 12);

c) relationships between different levels of the organisation, and the role of staff (chapter 13 and 14).

FACTORS FACILITATING AND HINDERING CONSUMER INVOLVEMENT IN MIND

Respondents in National and Regional MIND, in Local Associations with high consumer involvement (1), and in Eastvale and Westhill MIND were asked what factors they felt facilitated and hindered consumer involvement in MIND (2). Table 10.1 shows the factors which were most frequently mentioned (3).
TABLE 10.1
FACTORS SAID BY MIND RESPONDENTS TO FACILITATE OR HINDER CONSUMER INVOLVEMENT

<table>
<thead>
<tr>
<th>Facilitating Factors</th>
<th>National/Regional</th>
<th>Local Ass's with high C.I.</th>
<th>Eastvale and Westhill MIND</th>
<th>TOTALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Particular participants (consumers/professionals/laypeople/staff)</td>
<td>10</td>
<td>6</td>
<td>19</td>
<td>35</td>
</tr>
<tr>
<td>Organisational factors</td>
<td>4</td>
<td>5</td>
<td>11</td>
<td>20</td>
</tr>
<tr>
<td>Accessibility to consumers</td>
<td>8</td>
<td>2</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Presence or absence of opportunities/policies for consumer involvement</td>
<td>5</td>
<td>4</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Consumers' contributions/skills, or their lack</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Participants' attitude and beliefs about consumers</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Power issues</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Extent that consumer involvement is seen as salient</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Consumers' confidence/self-esteem, or its lack</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Consumers' experience of mental health problems</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Consumers' personalities or attributes</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Resources</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hindering Factors</th>
<th>National/Regional</th>
<th>Local Ass's with high C.I.</th>
<th>Eastvale and Westhill MIND</th>
<th>TOTALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants' attitude and beliefs about consumers</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Consumers' confidence/self-esteem, or its lack</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Consumers' experience of mental health problems</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Consumers' personalities or attributes</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Resources</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

310
### Table 10.2

**Participants Said by MIND Respondents to Facilitate or Hinder Consumer Involvement**

<table>
<thead>
<tr>
<th></th>
<th>Facilitating Factors</th>
<th></th>
<th></th>
<th>Hindering Factors</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>National Regional MIND</td>
<td>Local Ass's with high C.I.</td>
<td>Eastvale and Westhill MIND</td>
<td><strong>TOTALS</strong></td>
<td>National Regional MIND</td>
<td>Local Ass's with high C.I.</td>
</tr>
<tr>
<td>Consumers</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Professionals</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>MIND staff</td>
<td>8</td>
<td>0</td>
<td>3</td>
<td>11</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Council of Management/Executive Committee members</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Chairpersons of Local Associations</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Laypeople</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>
Most frequently mentioned were various MIND participants, including consumer and professional volunteers, and paid staff. Roughly equal numbers of respondents perceived at least one category of these participants as facilitating or hindering consumer involvement. However, overall, respondents mentioned a larger number of categories of participants who hindered such participation. Both consumers and professionals were perceived far more often as hindering, rather than facilitating, involvement (Table 10.2) (4).

Organisational factors were also frequently mentioned, with respondents referring, in particular, to channels for communication, and the extent to which structure, in different parts of the organisation, was formal or informal.

Smaller numbers of respondents mentioned the accessibility of MIND to people with consumer experience, and the latter's abilities. Frequently mentioned "hindering" factors included consumers' mental health problems and lack of self confidence, issues related to power, and attitudes towards consumers. The presence or absence of opportunities for participation, and related policies were described, and a number of respondents in Eastvale and Westhill MIND commented that the extent to which consumer involvement was perceived as salient was a significant factor.

Factors facilitating and hindering consumer involvement, mentioned by respondents and referred to in the literature, will now be examined in turn.
Firstly, the salience of consumer involvement will be considered: i.e., the extent to which MIND consumer and other participants considered it to be important. Some authorities stress that participation is facilitated or hindered by the extent to which consumers wish to be involved. Richardson comments that, whilst some writers have argued that many consumers desire to participate, others have questioned this, or stated that people will wish to participate only in specific circumstances (5). Alinsky comments: "collective action among [disadvantaged] people is possible only when a person fears threat to his own interests." (6). Chamberlin distinguishes between "professionally dominated" mental health services, and consumer run facilities, which are concerned with issues with consumers, themselves, define as relevant (7).

Lack of consumer participation, despite the encouragement of people in authority, has been described in Local Government projects (8), polities (9), planning social services programmes (10), health care (11), Community Health Councils (12), community mental health centres (13) and community organisation (14). A variety of reasons for lack of participation have been adduced, including indifference (15), apathy (16), passivity (17), and false consciousness (18). According to Graycar:

"..Countless studies have shown that participation in politics and in community affairs is very low." (19).
Edelston and Kolodner comment that when local people were invited to participate in US poverty programmes, there was “an apathetic response. Our experience produced no evidence that the poor are consumed with desire to partake of planning” (20). Feelings of powerlessness have sometimes been said to lead to low levels of participation (21). Marris and Rein comment that “apathy and social disintegration...robbed the poor of any power of initiative in their own interest” (22). Giner refers to sociological theories that political participation, through revolutions, only occurs amongst poor people when their “rising expectations are frustrated” (23). Some authorities comment that most people participate, in relation to issues which directly affect, and are of immediate concern to them (24). Verba et al note that “motivation comes from a preference for policies relevant to a social category of which one is a member” (25).

Several authors refer to the costs of involvement to participants, particularly time. Richardson comments that “from the participants' point of view, participation imposes a considerable burden, taking them away from their families and other pleasures, with no immediate gain for them. They have better things to do with their time” (26). Caro refers to the limited time which consumers have to participate in community mental health centres (27), whilst Klein and Lewis comment that the membership of Community Health Councils may be unrepresentative because only people with time to spare are recruited to serve on them (28). It has been found that the responsibility of running some self-help groups has fallen to a few people, with little participation of the bulk of the membership (29).
Belief that participation can work has also been described as a facilitating factor (30). Richardson comments that means other than participation may be used if these can more effectively achieve the desired end (31). Some authorities argue that beliefs in the value of participation depend, in part, on earlier socialisation experience (32). Pateman writes: "people who have a sense of political efficacy are more likely to participate in politics" (33), whilst according to Piven, a "sense of political inefficacy" reinforces powerlessness. "Low income people are overwhelmed by concrete daily needs... They have no belief in their ability to affect the world in which they live.." (34).

Other individual psychological factors have been described as contributing to a desire for participation. In employees these include "a high need for independence" (35), and a belief in control over one's life and high levels of motivation and achievement (36). Caine and Smail discovered that patients and staff who preferred to be participants in therapeutic communities had personalities which were more democratic and less authoritarian, compared with those who favoured traditional psychiatric wards (37). Kennard comments that, in mental health workers," informality, openness, liberalism, equality and democracy..are psychological tendencies which..lead towards the creation of a therapeutic community" (38).

THE SALIENCE OF CONSUMER INVOLVEMENT IN MIND

Reference has already been made to the salience of consumer involvement to many MIND participants, most of whom said they were in favour of increasing this in the organisation (39). In general,
consumer involvement was seen as resulting in more benefits than problems to individuals, but views on its effects on the organisation were more mixed. Whilst many people with consumer experience actively participated in Local Associations, few said that they had joined MIND for this reason. Some Local Association participants perceived consumer involvement as a good in itself, whilst others, especially in Eastvale MIND, stressed the valued ends which resulted to individual participants and/or to MIND (40).

Several respondents in Eastvale and Westhill MIND specifically referred to the extent that consumers wished to participate as a factor which could facilitate or hinder consumer involvement. A staff member of Westhill MIND commented: I think as more so-called consumers get involved .. it will snowball" (41). However, references to consumers' lack of wish to participate were more frequent in Eastvale and Westhill MIND, and this was often attributed to a lack of motivation.

"..Mentally ill members do not always turn up, so other people make the decisions. [People with consumer experience] may be enthusiastic at first, but their motivation can waver...". (Interview. Executive Committee Member, Westhill MIND).

"..[People with consumer experience] like to volunteer for subcommittees but getting them to turn up is a different thing altogether. They sit there like dummies waiting for others to do everything". (Interview. Executive Committee Member, Eastvale, MIND).
One Westhill MIND participant felt that many club members did not wish to participate because their hospital experience had encouraged them "to be lethargic. Staff do everything for them, give drugs and E.C.T.". Similar lack of motivation to participate was described in the local branch of the National Schizophrenia Fellowship which was studied, with two respondents commenting that members with schizophrenia did not want to be involved. Those who recovered often failed to stay in the organisation because they wanted to forget about their illness. Reference was previously made to the lack of participation, because of depression, of many members of Depressives Anonymous, and its effects on this organisation (42).

Although many consumers in MIND and the other organisations appeared uninterested in opportunities to participate, there were also many examples of involvement which had been initiated by people with consumer experience, and this will be considered next, beginning with a brief consideration of relevant literature.

**IMPELTUS FOR PARTICIPATION FROM CONSUMERS**

Whilst much of the literature describes consumers' reluctance to participate, several writers have described involvement which has been initiated by consumers themselves. Richardson relates this to increases in consumer demand, and consumers' rising expectations of services (43). Whilst middle class initiatives in participation have been emphasised (44), impetus from working class people has also been described, with Prochaska referring to considerable working class involvement in voluntary organisations from at least the nineteenth century (45). Initiatives from consumers have been described in education (46), planning, (47), housing (48), social services (49), community mental health centres (50), and poverty programmes (51).
A number of authorities found that American poverty programmes could not work if native leadership and aptitudes were ignored (52). Thus, Alinsky commented that leadership in such programmes must be indigenous, chosen by the people, and not by outsiders. "The building of a people's organisation can be done only by the people themselves" (53).

Several writers have described consumer movements which have led to increased participation. These include the rise of black power in the U.S.A. (54), the student movement (55), the increasing number of people using statutory services (56), and the growth of self-help groups (57). Kopolow, writing in 1981, commented "...today increasing numbers [of mental health consumers] are demanding that their... rights be respected and that they be given greater autonomy..." (58). The early nineteen seventies saw a considerable growth in North American Patients' Rights Movements, whose members protested at the bad treatment and dehumanisation which they had experienced as psychiatric patients (59). Similar movements of former psychiatric patients have developed in the U.K. and in other European countries, particularly from 1985 (60).

IMPETUS FOR PARTICIPATION FROM CONSUMERS IN LOCAL MIND ASSOCIATIONS

Reference has previously been made to Westhill MIND, which was founded and largely run by professionals, with little consumer involvement until the period of fieldwork; and Eastvale MIND, whose professional and lay founders involved consumers in the running of the Association...
from its inception (61). Information on the founding of eight Local Associations with high consumer involvement was collected. In five of these, consumers had been founding members of the Associations, and in three others, consumer involvement had increased in Local Associations which had previously been run by professional and/or lay members (62). In contrast to some Local Associations (e.g. those studied in pilot interviews) which were largely professionally run, certain Associations with high consumer involvement appeared to owe their existence, and many of their activities and services, to the participation of people with consumer experience (63).

"SEEDED OUT OF MY PROBLEMS"

Two Executive Committee Officers said that they had started their Local Associations because of their own experience of mental health problems. One of these respondents said that she and a friend had found it difficult to cope after being discharged from a psychiatric hospital. They benefited from the mutual support which they gave each other, and decided to extend this by setting up a Local Association for other people in similar circumstances. They were supported in their initiative by the local Regional Director and Regional Development Officer, and by a Social Worker (64).

The chairperson of another Local Association became involved because he felt grateful for the psychiatric treatment he had received.

"..I wanted to work as a volunteer in mental health.. I got in touch with [the local regional office]. This was how [the Local Association] was born: seeded out of my own problems..".

(Interview. Chairperson, Local Association with high Consumer Involvement.)
This respondent helped another individual with consumer experience (Ms B) to set up another Local Association in a neighbouring town, and introduced several volunteers into the new association. A survey of local needs was conducted by Ms B. and a social worker (65).

In three other Local Associations with high consumer involvement, consumers participated in organisations which had previously been run largely by mental health professionals. Mr and Mrs C. said that their interventions had revived an Association which had become almost defunct. Membership was low and heavily professionally dominated. Mr and Mrs C. joined following the death of their son, who had been diagnosed schizophrenic. Mrs C. had also, herself, experienced mental health problems. "When we went, we weren't coming back, because they (professionals) were talking shop", said Mrs C. However, they changed their minds, facilitated a relatives' self-help group, and became secretary and treasurer of the association.

"Northborough MIND" was started by a psychiatric nurse and had a committee of mainly mental health professionals, who, according to Ms. N, the Local Associations's secretary at the time of fieldwork, limited the amount of consumer involvement. Just before he left Northborough, the psychiatric nurse asked Ms. N. if she would be secretary. Ms. N. who felt strongly about here very damaging experiences as a psychiatric inpatient, agreed, and facilitated the involvement of other consumers and relatives in the Association.
Finally, Mr E. also decided to be involved in his Local Association as a result of his inpatient experience. Originally this was run mainly by mental health professionals, with some consumers on the Executive Committee. Mr E. eventually became chairperson, and also started another Local Association in a nearby town, with a committee consisting entirely of consumers and relatives.

The many ways in which people with consumer experience contributed to Eastvale and Westhill MIND has previously been described (66) with specific roles and responsibilities in the former Association, and opportunities for more informal participation in the clubs facilitated by Westhill MIND. Some club members said they appreciated opportunities to participate, and the lack of barriers between those members with, and those without, consumer experience. One individual commented favourably on the attitudes of other participants which, she said, had enabled her to take on responsibility for the running of a social club and luncheon club (67).

In both Eastvale and Westhill MIND, day centre and club members were often observed to spontaneously decide to take on responsibility. Participant observation suggested that it would have been impossible for Eastvale MIND to have run its day centre from 10 am to 10 pm, seven days a week, without the involvement of its members, who acted as stewards and took on other responsibilities. Although a few (non-consumer) Executive Committee members questioned day centre members' ability to raise funds, they were observed to be considerably involved in this area. Whilst decisions appeared to ultimately rest with the (non consumer) officers of the association, day centre members were, nevertheless, observed to be consulted and (in the case
of those who were committee members) to freely give their views in Executive Committee Meetings (68).

Responses to interviews suggest that consumers had been able to exert even more influence in some of the local associations with high consumer involvement. Several respondents described their own considerable participation, and in two cases, the facilitation of other consumers' involvement. When Ms. N. joined Northborough MIND, she determined to change the local association so that she and other consumers would have more participation. Initially, she was appalled at professionals' attitudes.

"...The people on the committee did harm to me because of their attitude of not finding what I or L (another consumer) said as valid... I could have dealt with someone saying "You've been in a loony bin" (rather) than their more subtle...feeling that I had no intelligence or perception of mental health problems."

"L and I. were...frustrated about what happened in the meeting... made ourselves unpopular by pushing for us to be listened to...".

(Interview. Secretary, Local Association with high consumer involvement).

Ms. N. felt there was a need for change in the Local Association. When the psychiatric nurse founder left, several other professionals also did so, and Ms. N. facilitated campaigning, and attracted, as Executive Committee Officers and members, a number of consumers, relatives and mental health professionals.
"..I was the main instigator [of consumer involvement] because of my own experience.. Now I've got allies..

(Interview. Secretary, Local Association with high consumer involvement).

Respondents in another Local Association felt that because consumers had founded the organisation, this had facilitated continuing participation through their contacts with other users of mental health services.

"..consumer involvement was successful because it was there at the start. It continued to be a process of [consumers] coming to the Local Association.. [who were] able to come onto the Executive Committee and be involved in decision making..

(Interview. Respondent in Local Association with high Consumer Involvement).

THE EFFECT OF CONSUMERS' SKILLS

Several writers have emphasised skills, qualities and abilities of consumers as facilitating their participation (69). Pateman quotes G.D.H. Cole, who believed that there were "large untapped reserves of energy and initiative in the ordinary man that a participatory system calls forth" (70). Smith comments that participation was valued in
Islington because consumers were seen by councillors as "an alternative source of local knowledge, advice and expertise." (71), Several authorities comment that individuals' self-confidence and raised consciousness facilitate their participation. Social psychologists have described the importance of heightened consciousness of oppression as a factor contributing to the participation of minority groups who are subject to discrimination (72). Chamberlin comments that raised consciousness and self-esteem facilitates the involvement of consumers in the setting up of alternative mental health services (73), whilst Verba et al comment that "knowledge and articulateness are important determinants of effective political systems", as are "prestige [and] political skill" (74).

Conversely, lack of skills and self-confidence has been seen as hindering participation (75). Pateman cites various studies of workers which suggests that lack of self-confidence was one factor which hindered their participation in various industries (76). According to Chamberlin, the internalisation of negative stereotypes of mental illness, held by laypeople and professionals, can contribute to consumers' lack of belief in themselves, and consequent difficulties in participation (77). Dyer and McAusland, referring to attempts to enable mental health consumers to participate, comment: "It was hard to understand all the things they said, and the anxieties they had expressed. There had been few opportunities to make choices and it took time and effort to begin to see some of the things that were important to them" (78). However, these authors conclude that such difficulties should not preclude consumers' involvement in planning services (79).
MIND respondents mentioned both benefits and problems related to consumers' skills, abilities and personalities. Whilst many people referred to gains from giving or receiving help, smaller numbers felt that participation caused difficulties for many consumers because of lack of skills or abilities (80).

Twenty-two participants mentioned the help and support which consumers gave others, but nineteen referred to problems from the participation of particular consumers because of factors such as personality or mental illness. Several respondents felt that problems were caused to the organisation from some consumers' difficulties in taking on responsibility or in making decisions, although a smaller number felt that participation enabled the provision of a better service (81).

In Eastvale and Westhill MIND, seventeen respondents mentioned a lack of skills as hindering, and only seven referred to specific skills as facilitating, consumer involvement (82). The effect of consumers' skills, or their lack, was also mentioned by other MIND participants.

A few respondents with consumer experience mentioned specific skills which they contributed to MIND. These included some National MIND volunteers, whose work in departments was related to their previous occupational experience in secretarial and library work. The chairperson of a local association with high consumer involvement described how his professional experience enabled him to campaign, as MIND representative on the local Community Health Council.
"..I'm .. probably the only person who's been mentally ill on the Committee.. and I find myself pursuing a somewhat lonely course and being rather forceful.. My MIND committees are just like a staff meeting.." (referring to his days as a schoolteacher).

(Interview. Chairperson, Local Association with high consumer involvement)

**CONSUMERS' SKILLS**

A number of respondents at both national and local levels mentioned lack of communication skills as a factor which prevented their participation, particularly on committees. Whilst some participants perceived the problem as related to consumers' lack of ability, others felt that the committee structure itself prevented participation (83). In addition, several respondents mentioned lack of self-confidence as preventing participation in the organisation (84).

One respondent felt that inarticulate consumers were likely to be excluded from debate within National MIND, whilst another referred to a "network of committees, with a charity network by invitation", which excluded people with consumer experience who lacked confidence.

"..To have a voice in MIND, you have to be.. very self-confident.. which is not easy for people with serious breakdown.."

(Interview. National MIND staff member).

"..People must have an ability of getting their point across.. Because of illness.. this can be quite a difficulty..

(Interview. Council of Management Member).
Several respondents gave examples of particular individuals whose illness or lack of skills had made it difficult for them to participate, and/or stressed the importance of communication or other skills.

"...People need to feel comfortable at sitting with others round a table. When someone puts forward a different viewpoint, they need to be able to take it on board, without falling apart. They need to know what's going on in relation to agendas and minutes."

(Interview. Chairperson, Local Association with high consumer involvement).

"...the reality is, people who are consumers can be pains at meetings. [It's difficult when] consumers come to meetings with a fixed idea, and disrupt it if their idea is not discussed. or if a consumer is not able to cope. or does not turn up [at a meeting] when she should."

(Interview. Assistant Director, National MIND).

This respondent added that similar problems could also occur with other participants who were not consumers.

Some respondents referred specifically to consumers' negative self-images as hindering their participation. One Assistant Director felt that certain volunteers in the National office had few
expectations from their involvement because of their impoverishment during many years' experience in long stay wards of psychiatric hospitals. A professional member of Eastvale MIND's Executive Committee commented:

"...The trouble is, [day centre members] bring with them the... [idea that] they can't make any useful contribution to anything..."

(Interview. Eastvale MIND Executive Committee member).

This view is reflected in the writing of several authors who describe individuals' negative self images as hindering their participation. This is often said to result from the failure of others, particularly professionals, to take their views seriously. (85).

THE EFFECT OF MENTAL ILLNESS ON PARTICIPATION

Chapter 9 included an account of respondents' mixed views about the value to MIND of consumers' views, perspectives and experience of mental health problems (86). Several respondents, all but one at local level, referred to consumers' mental health problems or personalities as hindering the participation of other consumers.

Interview data suggested that at least two local associations owed their existence to people who had founded them because of their experience as consumers (87). However, a few respondents saw mental illness as the only, or main factor which hindered participation (88).
"...Because of.. mental illness, people's capacities can fluctuate.. [Consumers] may want power, but not appreciate that it's hard graft..."

(Interview. Executive Committee member, Westhill MIND).

"...One of the characteristics of mental illness is unreliable and abnormal behaviour patterns, so people are prevented, in my view rightly.. from taking positions [in the Local Associations] which they are not prepared for, and capable of..."

(Interview. Chairperson of a Local Association with high consumer involvement).

"..I think the main thing with mental illness is lack of motivation, difficulty in keeping up constant commitment..."

(Interview. Staff member, Westhill MIND).

A number of authorities comment that effective participation depends on the ability of consumers to organise themselves (89), ensure effective dialogue between themselves and others (90) and to adequately advocate their views and rights (91). Such factors were not often mentioned as a facilitating or hindering factor by MIND respondents, although a few (non-consumer) Executive Committee members of Eastvale MIND referred to the lack of motivation of many day centre members, and the considerable help which was sometimes needed to enable them to participate effectively (92).
This section on the influence of consumers will conclude with a consideration of representativeness. Here, representativeness refers to the extent to which consumers who are members of an organisation, are representative of all consumers with similar problems. A number of authorities describe factors which affect the number and types of people who participate in particular organisations. These include the size of the organisation, which may limit the number of consumers who can take an active part (93), and the participation of certain people, which may facilitate or inhibit that of others. Thus, several writers have described the tendency of voluntary and other organisations to attract white middle class people, and provide participatory structures suited to their needs, with consequent inaccessibility to other would-be participants (94). In addition, styles of participation (e.g. co-operation and conflict) may attract certain people, but not others (95). Some authors describe the inherent racism, sexism or disablism of certain organisation (96), and emphasise the importance of ensuring adequate representation of all their constituency (97).

Reference has previously been made to the concern expressed by National MIND participants, during the period of fieldwork, about the inaccessibility of the organisation to (and consequent lack of participation of) consumers of black and minority ethnic groups and of women (98). In addition, a few people in Local Associations expressed concern about representativeness. Some authorities have referred to
the conflicting needs and interests of different consumers (99), and this was reflected in the views of one respondent, who voiced his strong concern that many other consumers in his local association were "left wing activists", who did not represent the views of himself or most other consumers. This respondent had suggested that the local association's "customer subgroup", of which he was a member, should overthrow its Executive Committee, but said that other members did not share his views (100).

A Social Worker on the Executive Committee of Westhill MIND commented:

"...Consumers may have idiosyncratic views, which may or may not reflect consumers. "The consumers you attract have a very limited representation of mental health consumers. They are likely to be middle class, articulate."

(Interview. Westhill MIND professional Executive Committee member).

However, such views were not often expressed, and overall, at local level, representativeness was not mentioned as either facilitating or preventing consumer involvement in general. In contrast, more concern was voiced, during the period of fieldwork, about the limited number of consumers who were serving on the Council of Management or in Local Association Executive Committees. The lack of representation of consumers on planning committees for statutory mental health and other services had also been described (101). A number of central
government reports have advocated the representation of service users on committees for social services (102), planning (103), school governorship (104), and health (105).

"..We would hope that consumers.. might be included in the main service committee or its sub-committees.." (106).

"..People must be able to participate more fully in the planning process.. One of the government's main aims.. is to ensure that there are greater opportunities for the discussion of important changes while they.. can be influenced by the people whose lives they will affect.." (107).

In January, 1986, a D.H.S.S. Draft circular ("Collaboration between the N.H.S. Local Government and Voluntary Organisations") recognised the contribution which consumers could make to the planning of mental health services.

"..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 that plans are seen by consumers.." (108).

More recently, the Wagner Report and Social Services Inspectorate reports on residential care, and the white papers "Caring for People" and "Working for Patients" have stressed the importance of choice, and of considering consumer views (109). According to "Caring for People", local authorities ".should establish procedures for
receiving comments and complaints from users of services." (110); and "...consult with and take account of the views of... representatives of service users and carers in drawing up their plans." (111).

However, several authors have commented on the lack of representation of consumers and their relatives in the planning of statutory mental health services (112). "One survey reported that.. 50 per cent of District Health Authorities, when asked about their plans to involve users in planning services, actually felt it was "irrelevant" to involve users and had no plans to do so" (113). MIND and a number of other voluntary organisations have advocated such involvement (114). According to a National Council of Voluntary Organisations Working Party: "client participation in the management of an organisation is one way of enhancing the service's accountability to the client group. "participation... [is] a contribution to effective management" (115). Recently, a few District Health Authorities have involved consumers and relatives in the planning of mental health services, or have stated a commitment to do so (116). However, Murphy comments that such involvement can be tokenistic and unrepresentative of consumers as a whole (117).

Previous reference has been made to the views of most MIND respondents that there was insufficient consumer involvement at all levels of the organisation, including Council of Management, and to steps taken to increase this (118). In addition, concern about the lack of consumer involvement in Local Association Executive Committees was expressed by some respondents (119). In 1985, a document was produced which recommended that Executive Committees should include equal numbers of consumers, laypeople and professionals (120). This was subsequently
approved by Council of Management, who agreed that, in future, Local Associations would have to have such an Executive Committee in order to be affiliated to National MIND (121). It was believed that increased consumer representation at local level would result in greater consumer involvement in Regional Councils and in the Council of Management (122).

Whilst the participation of consumers in some Local Associations facilitated the involvement of others (123), in Westhill MIND the large numbers of non-consumers on the Executive Committee was said by many respondents to hinder consumer involvement. This was debated in a number of the Association's meeting.

"...I think perhaps some... consumers could see the number of professionals on the Executive Committee... as being intimidating..."

(Interview, Westhill MIND, Executive Committee Officer).

"...Having a psychiatrist as Chairperson I think is very alienating for people and a statement about Westhill MIND which is very damaging... We must do something about... professional dominance, which is intimidating..."

"...Consumers are reluctant to be involved and are intimidated, especially with professionals. I think it's never been resolved. There's a huge gap and Us and Them feeling..."

(Interviews, Westhill MIND staff members).
CONSUMERS' ATTITUDES

Data from interviews suggested that people with consumer experience had facilitated the participation of other consumers in at least three Local Associations with high consumer involvement (124). In contrast, a few respondents mentioned that the attitudes or personalities of particular consumers prevented others with similar experience from participating. One Eastvale MIND day centre member was perceived by some respondents to be dominating and controlling, and participant observation suggested that this was sometimes the case (125). A few participants implied that this individual sometimes made it hard for other day centre members to participate. A respondent in another Local Association referred to the dominance of one individual, who made decisions on behalf of other consumers because he felt they lacked sufficient ability to put forward suggestions of their own. A few other respondents described argumentative, obstructive or offensive attitudes in people with consumer experience as hindering participation.

Some of the literature on participation has emphasised problems resulting from the attitudes of professionals (126), but there appears to be less mention of the adverse effects of consumers' attitudes. Chamberlin comments that consumers, as well as professionals, can experience mentalism (prejudiced attitudes towards people perceived as having mental health problems). "Ex-patients must deal with their own mentalism before they can challenge the mentalism of others". (127).
PUBLIC ATTITUDES

The attitudes of both members of the public and of professionals have been described as having adverse effects on people with mental health problems. In a variety of cultures, such people have been widely stigmatised, feared and seen as lacking rationality or responsibility (128). Early voluntary organisations, initiated by laypeople and professionals, appear to have seen people with mental health problems as objects of charity, in need of help and guidance, rather than as equal participants (129).

A number of authorities have described prejudiced attitudes from the public when people with mental health problems have moved from hospital to community facilities. According to Brown:

"...Mentally ill persons have historically been a stigmatised and brutalised population. Despite large-scale attempts in recent years to reverse public antagonism, dislike and fear of mental patients has continued. Deinstitutionalisation has brought the mentally ill in closer proximity with the general public, thus increasing social fears and hostility, despite concerted attempts to allay such attitudes.." (130).

In Bellin's view, it is stigmatising to differentiate between consumers and non-consumers on Executive Boards of Community Mental Health Councils. "It's nobody's business whether they are clients or
not" (131). This view was reflected in the responses of a number of National MIND participants who felt that it would be stigmatising to differentiate between "consumers" and "non consumers" on the Council of Management. In contrast, other respondents felt that if participants "came out" and declared their consumer experience, this would facilitate the participation of other consumers (132).

Reference has previously been made to "covert consumer involvement" in National MIND: participants who had experienced mental health problems, but who did not make this explicit (133). A few respondents stated that consumer involvement was hindered because of a lack of people in prominent positions in National MIND who had both experienced mental health problems, and were prepared to make it clear that this was the reason for their involvement in the organisation.

"..I think the first thing would be an open commitment to..advertising prominent people in the organisation who are examples.. We need a couple of people as figureheads.".

"..I have difficulty with the idea of a consumer advisory [network]. It's like "Them and Us."..I want it to be known that anyone can have psychiatric experience..that when people are depressed, psychotic, they can make valid, clearer decisions: maybe clearer because of their experience..

(Interviews. National MIND staff members).
Few respondents specifically mentioned laypeople (i.e. people who did not have consumer or professional experience of mental health problems) as facilitating or hindering consumer participation in MIND. In one Local Association with high consumer involvement participation was initiated by a Regional Director, who asked a prominent local man with a lay interest in mental health to become involved, in order to facilitate consumer involvement. This respondent described how he ensured consumer membership by "autocratically imposed democratic methods." (134).

In Eastvale MIND, lay members and officers of the Executive Committee were observed to facilitate the participation of day centre members in the running of the centre and in open meetings and Executive Committee Meetings (135). However, three committee members complained that the officers of the Association (two of whom were lay, and one a professional) sometimes made decisions which went against the views of the committee as a whole. One Executive Committee member with consumer experience complained that a lay officer vetoed decisions which were made by himself and other consumer members of the fund raising subcommittee (136).

Interviews with a few lay members of MIND suggested that their attitudes towards consumers, and their beliefs about the latter's ability to participate, might have affected consumer involvement.
Thus, two lay members of Eastvale MIND's Executive Committee described day centre members as "tunes" (137), and gave repeated (and in the interviewer's private opinion, derogatory and scornful) examples of their inability to cope with responsibility. However, such a view was very unusual amongst Eastvale MIND and other respondents. A married couple in a local association with high consumer involvement, whose participation was brought about because of a relative's mental illness, commented:

Mrs C. "Oh, no .. we wouldn't like to push them in any way .. you can't rely on them in any way ..".

Mr C. "They're not up to responsibility".

Mrs C. "Some can and some can't. We tend to let them come and go as they wish".

(Interview. Respondents in a Local Association with high consumer involvement).

During the period of fieldwork, the National Schizophrenia Fellowship (N.S.F.) placed considerable emphasis in its literature on the participation of relatives with a diagnosis of schizophrenia and of the organisation's medical advisors (138). However, little mention was made of the participation of people with experience of schizophrenia (referred to as "sufferers"), although there were several references to their difficulties in being involved in decision making and responsibility (139).
"..Schizophrenia is an illness which can seriously affect the.. ability to make reasoned decisions, organise effectively, or present views coherently. N.S.F. wishes sufferers, families and carers to be consulted about treatment, care and services as much as possible, but feels from experience that it is impractical to expect sufferers to run their own services.." (140).

Four Executive Committee members of the Westhill branch of the N.S.F, including one individual who said he had experienced schizophrenia, expressed more reservations about consumer involvement than respondents in other voluntary organisations which were studied.

A. "..I don't think Head Office like them to have a lot of responsibility in a branch..".

B. "..They are bound to be unreliable, not stable. It's all they can do to go to work, and get up.. and look after themselves..".

(Interview. Executive Committee members of Westhill branch of the N.S.F.)

Another Executive Committee member said that, although "sufferers" had opportunities to participate in the Westhill branch meetings, few took an active part. This was also observed by Levy in his study of an N.S.F. branch in London (141).
Given that there were opportunities for consumers to participate in an organisation whose main aim is the support of relatives of people with schizophrenia (142), it can be questioned how far the limited consumer involvement was caused by: a) the effects of schizophrenia on the motivation of people with this diagnosis; b) the beliefs held by relatives and medical advisors that schizophrenia made it difficult for sufferers to participate. It is suggested that the participation of particular consumers may be affected not only by specific mental health problems, but by their own beliefs and perceptions, and those of laypeople and professionals, about the extent to which these make it possible for them to be involved. The lay founder of the N.S.F. commented on a collection of personal accounts of schizophrenia:

"..to the extent that our contributors are among the successes thrown up by the illness..their accounts may not be wholly representative." (143).

"..the most literate and articulate..speak for the large majority of their fellow sufferers who find it much more difficult to express themselves.." (144).

In contrast, Manic Depression Fellowship (MDF) respondents described both benefits, as well as problems, from the participation of "sufferers" (145) who played a large part in the running of the organisation. According to one respondent, the National Committee consisted of eight sufferers and four relatives, and "we're not sure who's whom" (146). Whilst in the N.S.F. it was relatives who used the media to disseminate an understanding of people with schizophrenia and
their families, in the MDF a number of sufferers had written about or broadcast their experiences (147).

It could be argued that differences in the amount of participation of consumers in the two Fellowships was related to participants' perceptions of the nature and effects of schizophrenia and manic depression. Some of these perceptions appeared to mirror those of the authors of psychiatry textbooks. People who had been diagnosed schizophrenic appeared to be seen by respondents and by the writers of N.S.F. literature as often lacking motivation and the ability to take on responsibility, and sometimes as being chronically disabled. Respondents in the M.D.F. indicated that many of their members might be very ill during a phase of depression or hypomania, but that such episodes were usually short-lived, and at other times they were well, and often successfully followed professional occupations (148).

**SUMMARY**

Respondents were asked what factors, in their view, facilitated and hindered consumer involvement in MIND. Most frequently mentioned, as both "facilitating" and "hindering" factors, were particular participants, organisational factors, accessibility to consumers, and the presence or absence of opportunities/policies for consumer involvement. Both consumers and professionals were perceived more often as hindering, rather than facilitating, such participation.
Although the literature includes many examples of consumer movements which have led to increased participation, several authors havecommented on the lack of salience of participation to many consumers. A variety of reasons for this have been suggested, including apathy, a sense of powerlessness, and the costs of involvement, particularly time.

Some MIND respondents, especially in Eastvale and Westhill MIND, commented that factors, such as a lack of motivation or interest, hindered the participation of some day centre and club members, but there were many examples of consumer involvement in these Local Associations, and the running of the day centre depended on the considerable amount of responsibility undertaken by some members. In addition, several instances were found of participants who had founded, or become actively involved in, an Association because of their wish to use their consumer experience for the benefit of others. Some of these individuals had facilitated the participation of other consumers.

In the literature, consumers' skills, abilities and personal qualities have been seen as having a crucial effect on participation. Whilst many MIND respondents described the help and support which consumers gave each other, there were almost as many references to problems caused by their personality traits, attitudes or mental health problems. Lack of self-confidence and difficulties in communication were often mentioned as preventing consumer involvement. Examples of individuals using their skills, and their experience of mental illness to help others, were often given, but some participants, particularly
in the National Schizophrenia Fellowship, described resultant problems, such as lack of motivation.

Studies have found little consumer representation in the planning of statutory mental health services. Some respondents expressed concern about the lack of people with consumer experience on Council of Management and Local Association Executive Committees, and it was decided, shortly after the period of fieldwork, that Local Associations would be required, as a condition of affiliation, to include equal numbers of consumers, laypeople and professionals on Executive Committees. A few respondents questioned the extent to which actively involved participants adequately represented other consumers.

Finally, prejudiced attitudes towards people with mental health problems have been widely described. Whilst some respondents felt that it would be stigmatising to differentiate between "consumers" and "non consumers" on the Council of Management, other respondents felt that, if people in prominent positions in MIND "came out" and declared their consumer experience, this would facilitate the involvement of other consumers. Interview responses suggested that consumer involvement could be affected by lay and professional participants' beliefs about the extent to which mental health problems affected consumers' ability to take on responsibility.
Much has been written on the influence of professionals on consumer involvement, and this was also mentioned by many MIND respondents. In the literature, professionals’ initiatives to increase participation have been described in a variety of fields, including planning (1), housing (2), education (3), community work (5), health and education (6), nursing (7), general practice (8), therapeutic communities (9) and self help groups (10). In the U.K., from the nineteen sixties, there has been emphasis in the social work literature on client self-determination, and on considering clients’/patients’ perspectives (11). From the seventies, (and earlier in the U.S.A.), some community workers have enabled consumers to actively participate, sometimes politically, in making changes in their neighbourhoods (12).

Some sociologists have described the power which has been accorded by western societies to certain professions (notably the church, the judiciary, and from the mid nineteenth century, medicine); and laypersons’ largely uncritical beliefs in the expertise of members of these professions (13). However, from the nineteen seventies, there
has been an increasing volume of literature criticising certain professions for being agents of social control, and for exerting excessive power over education, health and other aspects of the lives of laypeople (14). In particular, medicine has been criticised for creating a "mystique" about matters concerning health, for ignoring patients' perspectives, and allowing them little participation in their care (15). "...By transforming pain, illness, and death from a personal challenge into a technical problem, medical practice expropriates the potential of people to deal with their human condition in an autonomous way." (16).

Since the fifties, critical analyses of the doctor - patient relationship have examined distributions of power within this dyad, and ways in which patients can be consulted and enabled to participate in their care (17), with the production of various models of the Doctor - Patient relationship to enhance understanding of varying degrees of patient participation (18). Accounts have been published of ways in which the Peckham Health Centre, and more recently, the Lambeth Community Care Centre, have developed participatory structures to involve patients in their care (19). From the late seventies, an increasing number of patient participation groups have developed in general practice (20). There has also been an increasing interest in patient participation in nursing, with the development of nursing models (21) and primary nursing and other individualised forms of care, which stress the importance of patients' perspectives of need and their active involvement in decisions concerning their care (22).
Professional attitudes in relation to the individual consumer's ability to make decisions are said by many authorities to affect participation, and reference has previously been made to the effect of the beliefs of those in authority on consumers' self-determination, motivation, skills and ability to take on responsibility (23). Richardson comments that participation can be inspired by "the need to offer consumers some protection against the domination of decisions by entrenched professionals" (24). According to Clode et al, such domination decreased during the Thatcher Governments from 1979. Prior to Mrs Thatcher's election as Prime Minister:

"..[the] attitude with which both consumers and producers had approached their services [was] paternalism. With the breakdown of the shared expectations that paternalistic modes of behaviour imposed on both client and worker/teacher and taught/doctor and patient, culminating in 1979 with such a loss of confidence in the good faith of suppliers of public welfare, consumerism seemed the only possible ideology left untried." (25).

Much has been written about ways in which professionals and others in authority hinder participation. Professionals have been criticised for creating unnecessary barriers between themselves and clients (26), being controlling (27), paternalistic (28) and denying the consumer perspective (29). Other problems include differences, between client and professional, in social class and belief (30), communication difficulties (31), clashes of perspectives (32) and conflict of interests (33). Consumer participation is said by several authorities to be threatening to professionals because it affects the distribution of power within
organisations or professional - client relationships (34). "Pseudo-participation", where professionals use participation to manipulate consumers, or in a tokenistic way, has previously been described (35).

MENTAL HEALTH PROFESSIONALS

Many critics of British mental health services have described conditions which ignore the needs and perspectives of consumers, and which fail to give them sufficient choice, freedom or responsibility. In the U.K. from 1969, a succession of central government enquiries have reported such conditions in psychiatric and mental handicap hospitals, with, in some cases, instances of neglect and cruelty (36). In addition, from the fifties, many social scientists and mental health professionals have described ways in which hospitals have dehumanised patients, stripped them of their identity and dignity, and forced them to conform to all-pervasive, institutionalised regimes (37). Several antipsychiatrists and other authorities have argued that mental health workers, both in institutions and the community, are agents of social control, who keep in order various "deviants", who fail to fit into the smooth running of society (38). In addition, some Marxist proponents have referred to mental health workers as the tools of capitalist society: warehousers of people who are economically unproductive (39). However, antipsychiatry and "critical sociologies of madness" have
been criticised for not appreciating the complexity and variety of mental health work, or the moral dilemmas which professionals face (40).

The early seventies saw the beginnings of patients' rights movements in the U.S.A. and Canada (41) and in the U.K, where there was a considerable increase in membership from the mid eighties (42). Whilst some former patients have written favourable accounts of services (43), an increasing number have criticised professionals for controlling, condescending and cruel attitudes, and for providing facilities which are dehumanising and institutionalised. Professionals' treatment of patients as if they were irresponsible and unable to make decisions or choices has also been described (44).

Since World War Two, there have been various reforms in mental health services, some in response to the writing of critics (45). These have included the spread of more liberal institutional regimes and the growth of the therapeutic community movement (46), developments in community care (47), and principles of normalisation (48). In the last decade, there has been a growth in individualised psychiatric nursing care, with the development of primary nursing (49) and the application of nursing models in which patients' perspectives are considered (50). The 1989 white paper "Caring for People" placed importance on each mental health client receiving individualised packages of community care, co-ordinated by a keyworker (51).
These developments have emphasised the importance of individual needs and choices, and of service users' participation in their care. However, a number of critics have commented that certain of these changes are reformist, rather than radical, (52) and have not resulted in real changes in attitudes or redistribution of power. Thus, several critics have pointed out that "community care" facilities continue to dehumanise clients with mental health problems (53). Therapeutic communities have been criticised by some consumers for "pretending" to be democratic, rather than giving real power to their residents, and for being "false alternatives" to more radical approaches (54). Such criticisms are borne out, to some extent, by the research of Sharp, who found that staff controlled decision making, despite commitments to ideals of democratisation (55).

"PARTICIPATION BY" VIA "PARTICIPATION FOR"

Chamberlin criticises hospital-based therapeutic communities for their domination by professionals, who fail to offer residents "real" participation and power (56). Both Brager et al and Graycar refer to the ways in which participation, leadership and professional expertise "each competes for ascendancy in community life" (57); whilst Webb and Robb describe ways in which "professional and bureaucratic hierarchial and professional knowledge can hinder participation" (58).
Several writers make a distinction between "participation by" and "participation for" consumers (59). According to Holland, President Kennedy criticised poverty programmes in the USA, for "planning programmes for the poor, not with them" (60). Professionals' imposition of policies, and the passivity of disadvantaged people, are described by a number of writers. Wilson comments that, in the U.S.A., "..such people are usually the objects, rather than the subjects of civic action: they are acted upon by others, but rarely initiate action. As a result, they often develop a keen sense of the difference between "we" and "they.." (61). Blunkett writes of social services consumed in the U.K.:

"..We have not provided services with people, we have provided them for people. In part this has resulted from the way in which the new Seebom departments were constructed .. a new group of welfare "experts" - social workers - were established .. so services end up by being something given to people .. not something people can participate in and feel to be theirs.." (62).

A distinction has been made between partnership and separatist forms of participation. The former refers to consumers working in conjunction with professionals and/or other people in authority and supportive laypeople. In separatist forms of participation, members of an identified group form their own organisation, work largely on their own, and make their own decisions about whether to involve "non-consumers" (63). Separatist participation has been described in relation to survivors of mental health services (64), black people (65) women (66) and people who are lesbian or gay (67).
Chamberlin criticises "partnership" models of professional-client relationships in mental health, arguing that terms for participation are laid down by the professional, with little real consumer involvement. According to this author, patient-run alternatives follow supportive or separatist models. In the former, consumers invite particular professionals to be involved, and themselves decide the extent and nature of professional participation. The separatist alternative is run completely by consumers, with no involvement from professionals (68). Barker and Peck point out that separatist movements make it easier for people with shared experiences to meet together, apart from other people. This "has enabled them to reshape their understanding of the world and reject the "received wisdom" of the dominant. From this power base they are challenging and changing their worlds." (69).

Both Campbell and Fowler comment that, whilst North American patients' rights movements have tended to be separatist, in the U.K. many such groups have involved both consumers and professionals (70). According to Campbell, a feature of Survivors Speak Out (an umbrella organisation of British mental health consumer groups) is that:

"..its membership includes both "survivors" and "allies" .. It is non-separatist, and in this way differs from mental health self-advocacy in most other countries.. the general atmosphere is mainly one of "working together" (71).
Campbell adds that some British professionals have "played a significant part in enabling groups like Survivors Speak Out to get off the ground" (72). He comments that the advantages of working with professionals include the skills and credibility which the latter can contribute to enable consumers to exert influence. Professionals and consumers may be able to work together to produce changes which they both desire, but problems include consumers' perceptions that professionals have been involved in disempowering them, with the consequent surfacing of powerful emotions; and the danger that professionals will dominate the group (73). Fowler comments:

"...The attempt to keep the group control with consumers may require quite formal, will planned organisation. The very fact of having to undertake this process may influence the kind of consumer involvement which the group undertakes." (74).
PROFESSIONALS IN MIND

Many MIND respondents stated that the attitudes of professional participants in the organisation were particularly crucial in facilitating or hindering consumer involvement. At local level, there were many comments about the attitudes of professional members of Executive Committees. In National MIND, expressed views on the staff employed by MIND were more frequent, although a few people commented on professional members of the Council of Management, particularly psychiatrists.

Some respondents viewed professionals' desire for, and encouragement of consumer involvement as crucial to its development. Thus, a staff member of Eastvale MIND commented. "I think all the Executive Committee do encourage the members to participate" (75). In this Local Association, the social workers who facilitated its setting up, encouraged the involvement of consumers and laypeople from the start (76). In one local association with high consumer involvement, the social worker chairperson was said to have had a style of leadership which facilitated participation. In Westhill MIND, the efforts of certain participants were seen as encouraging an increase in consumer involvement:

"..When we have had consumers involved, this has been through a big effort to get them to come [to meetings]. We've provided lifts."
"...When there was controversy about a Group Home, ...the chairperson invited [residents] to ... a meeting. Some... appreciated being able to see how the Executive Committee works..."

(Interviews. Westhill MIND Executive Committee participants).

A few other Westhill MIND respondents commented on the importance of listening to consumer views.

"...You have to have a hotline to the people who use services before you say ECT... or drugs are bad... to give a more balanced view..."

(Interview. Westhill MIND professional Executive Committee member).

Other respondents commented that a lack of interest in consumer views, or a dominance of professional views, was inimical to consumer involvement.

"... The Executive Committee's our biggest bone of contention... A major problem is that we're perceived as being frightening, distant, full of professionals. I think all these things frighten people off..."

(Interview. Westhill MIND professional chairperson).

This respondent added that the Executive Committee "agonised constantly" about consumer involvement, without coming up with ready solutions. However, this debate did appear to result in some action, as consumer involvement in the organisation had increased within a few months after the period of fieldwork (77).
A number of respondents commented that professionals needed to be especially aware of their tendency to dominate decision making, and to consider ways to facilitate participation.

"..the most important thing is how the..professionals behave..If you happen to be a [professional]...you provide a peg on which people can hang all sorts of notions. If the professionals act in a facilitative way, indicating that they have as much to learn as anyone else, then that helps.. It’s a lot easier for professionals to damage then to facilitate consumer involvement..".

(Interview. Professional chairperson of local association with high consumer involvement).

The work of MIND staff members in encouraging professionals' attitudes to facilitate consumers' involvement is described elsewhere in this thesis (78).

In two local associations, inappropriate attitudes of professionals were said to indirectly facilitate consumer involvement. In one case, a social worker was said to have alienated other professionals, who then left, leaving a largely consumer membership. Consumer involvement then increased because of the absence of professionals. Previous reference has been made to the consumer secretary of an association who was so appalled at the attitudes of professional Executive Committee members that she determined to increase consumer involvement (79).
Many respondents, particularly in Westhill MIND, referred to issues related to perceptions of power of professionals and consumers. Several authorities describe the curtailment of consumer participation by professionals and others in authority to avoid limitations or threats to their own power. This occurred in poverty programmes in the U.S.A. in the sixties, when consumer-initiated participation was curtailed, with cuts in funding, when it was perceived as being too radical by those in power (80). According to Leo Smith, in Local Government in the U.K:

"..The more matters become "professional" matters (i.e. not subject to public debate or democratic control) the less participation there will be. It is a means of defining a sphere of influence which cannot be penetrated by outsiders - of increasing the power of the professional.." (81).

Accounts of the coercive nature of many psychiatric institutions have previously been outlined (82). Many critics have described the excessive and inappropriate use of power in both British and American traditional psychiatric institutions (83), and in therapeutic communities (84) and community services (85) unequal power relationships between psychiatric patients and professionals have been described (86).
Several authorities describe limitations of power of consumers in mental health organisations which, ostensibly at least, have encouraged participation (87). Kopelow refers to the professional view of "mental illness as a disabling condition" and to professionals' status and associated power (88). According to Pargament, participation is a threat to medical models of care (89), whilst Windle and Paschell state that, in USA community mental health centres, "...the views of the client are likely to be regarded as of little value and possibly as illegitimate" (90). Several medical sociologists have described imbalances of power in doctor-patient relationships, although examples of negotiation and equal partnerships, and of relationships where the consumer is in control have also been described (91).

According to many critics, relationships between consumers and mental health workers, especially psychiatrists, have been characterised by paternalism: "...professionals [making] choices about the treatment of patients or clients which they deem to be in those clients' best interests..." (92). In psychiatry paternalism has been related to beliefs that people with mental illness have limited rationality: the ability of the individual to define her/his circumstances and interests "and communicate these to others, and to act responsibly by seeing the need for relationships based on mutual rights and obligations" (93). The notion of limited rationality in users of mental health services is related to that of determinism: that their thoughts, speech and behaviour are caused by mental disorder, which is the result of factors such as biochemical abnormalities or early life experience, over which the individual has little or no control (94).
Deterministic notions of mental disorder tend to stress the individual's limited ability to make rational decisions, and to exercise free will, because of the constraints of his illness. Compulsory treatment and admission to hospital are justified on the grounds that the individual, if rational, would wish to be protected from harming herself/himself or others, and would wish to be treated (95).

Some critics state that mental health professionals have tended to overemphasise the irrationality of people with mental health problems. Milner points to inconsistencies in the concept, and comments that, in relation to schizophrenia "psychiatry adds imagery that increases the emphasis on irresponsibility, unpredictability and dependence" (96). Ramon describes the development of ideas in psychiatry which ignore the patient's perspective.

"...The psychiatrist is instructed to evaluate the form of the patient's message and not its content. Invalidation of the person's perception of his own experience takes place from the beginning. Instead, the meaning is given by the psychiatrist as an objective observer." (97).

Critics of psychiatry, including consumers, have commented that many mental health workers have assumed that all communications, emotions or behaviours of patients are invalid and irrational (98). Thus, Rosenhan, reporting on his experience as a "pseudopatient" participant observer, described how staff misinterpreted ordinary requests and behaviours as evidence of psychosis (99). Campbell, a former user of mental health services, comments:
"...The [psychiatric] concept of lack of insight... [erodes] our position as competent creative individuals. If I am to be confined to a category of persons whose experience is devalued, status diminished and rational evidence dismissed, simply because at a certain time... I lost contact with the consensus view of reality... then it is scarcely possible to expect that my control over my life will ever be more than severely circumscribed. If my experience is not valued, I cannot be whole. It is in particular discouraging to speak to some psychiatric professionals, and have my experience validated only as a...sad blemish in an otherwise benign conception. This is no validation whatsoever." (100).

POWER AS A COMPONENT OF PARTICIPATION?

Several authors have commented that power is a crucial component of participation, and many have argued that, for participation to work, there must be a redistribution of power within an organisation or society (101). Jaques defines power as "...the quality of an individual (or a group) which enables him to influence other individuals, either singly or collectively, by channelling and directing their behaviour in such a way as to help him to fulfil his aims. It is that quality which gets others to act, to work, to do things on one's behalf." (102).

The importance of increases in self-empowerment has been described: the raising of consciousness of consumers, and enabling their appreciation of their abilities, value as individuals and capacities to influence decision making (103).
In addition, the attitudes of professionals and others in positions of authority have been seen as crucial in effecting real shifts of power. Facilitative attitudes have been described (104), but may authors describe ways in which people in authority have ignored indigenous leadership, manipulated consumers, allowed participation only on their terms or used it for their own ends (105). Contrasts have been drawn between real shifts in power and the co-option of consumers (106), and the use of "participation" to legitimise actions taken (107).

Some writers view the redistribution of power as essential if participation is to be meaningful (108). According to Pateman, participation in industry "involves a modification... of the orthodox authority structure" (109), whilst Graycar comments that "participation is only of use with power" (110).

I suggest that such a view is problematic for the following reasons.

1. It ignores the complex nature of participation. The present study, and the work of some authorities suggests that there are several degrees of participation (including information and consultation), not all of which involve marked shifts in power (111).

2. Both the literature, and the present study suggest that some people with consumer experience (e.g. some day centre members in Eastvale MIND) are happy to participate in ways which do not involve having much power in the organisation. Many MIND consumers welcomed the
opportunities to take on responsibility and put over points of view, but said they did not wish to be involved in running the organisation at either local or national level (112).

3. Much of the literature fails to consider the complex nature of "power" or to distinguish between "formal powers" and "actual powers": power which is exerted in reality (113). An individual may have little formal power, but exert considerable informal "behind the scenes" influence (114). I suggest that power, like participation, is a multi-dimensional concept. E.g. within an organisation, an individual might exert considerable power in some ways and little in others. Industrial sociologists have distinguished between individuals with formal positions or authority in work organisations, and those with other forms of influence, such as informal leaders amongst a group of shop floor workers. It has been found that, in some ways, such informal leaders may exert more influence over the workforce than managers in formal positions of power (115).

POWER IN MIND

A number of respondents, most of them National MIND staff members, referred to participants' ability or willingness to accept shifts of power within the organisation as a factor which hindered or facilitated participation. In addition, a much larger number of people referred indirectly to power issues, and most of the other factors affecting consumer involvement which were mentioned by respondents are related in some way to power. These included the attitudes and roles of various participants, and their willingness, in particular, (especially in the case of professionals) to be
open to, and learn from consumer views and experiences, and to ensure that they (i.e. other participants) did not dominate decision making. Consumers' skills, self esteem and willingness to participate appeared to be related to ideas of empowerment, including beliefs about their value and worth as individuals (116). Organisational factors also seemed to be related to power. E.g. some respondents commented that the structure of meetings, and the language used, often reflected a largely middle class "non-consumer" authority. Several staff felt that the extent of policies and opportunities to participate was an indication of participants' commitment to increase consumer involvement (117).

Five Council of Management members were asked to compare the amount of influence (a consequence of power, according to Jaques' definition (118) of consumers, on decision making in National MIND, compared with five other groups of participants. Four respondents rated consumers sixth, and one ranked them fifth. Other respondents, although not asked this question, (119) stated that consumers had little influence in National MIND, compared with other participants. Most respondents rated as "nil", "slight" or "not enough" Council of Management's and staff's consultation of consumers' views and their involvement in decision making and responsibility, and overall influence on National MIND policy (120).

Eleven National MIND respondents referred to factors related to power which militated against consumer involvement, and there were few references to facilitating factors in this respect (121). Several National MIND staff described basic inequalities between themselves and volunteers, which were said to be reflected in the latter's lowly status, and tasks, poor work conditions and the negative attitudes of many staff towards them (122). A few respondents felt that these factors hindered consumer involvement.
"I think they feel superfluous, without a role, nowhere is their space."

"I think the problem has been lack of role, and a confused sense about status."

(Interviews. National MIND staff).

Some respondents referred to barriers between consumers and other participants as hindering consumer involvement.

"To the extent that professionals dominate the Council of Management, I'd say that's negative."

"We mirror the power structure in MIND."

(Interviews. National MIND staff).

Several people mentioned problems concerning redistribution of power as limiting consumer involvement, although some referred to organisational changes which would result in increased power to consumers (123). A few respondents said that increased consumer involvement would cause changes in the power or status of other participants which they would find hard to relinquish. Respondents in Westhill MIND, as well as at national and regional levels, described this as a problem. A regional director, who felt particularly strongly about this issue, commented:
"..I've been suggesting [consumer involvement] for the last seven years...people are always very pleasant...but have not responded, and I think there are good reasons why not. Consumer involvement has consequences for some groups of people to give up power. [They think:] "we can have a nice discussion, but at the end of the day, if you ask me to give up power, I'm reluctant."

(Interview - Regional Director).

An Assistant Director felt that it would be difficult to change MIND's structure to increase consumer involvement because of staff insecurity and:

"..the professional fears of losing status...control...power... If you can say you're on a committee with Lord X and Dr. Y, it's different to saying you're on a committee with Joe Bloggs [a consumer]...it comes down to...fears about one's own position...and a "them and us" situation re the mentally ill...".

(Interview. National MIND Assistant Director).

Another staff member felt that there were:

"..always going to be certain suspicions about the role of people in the organisation who are not staff...postholders may feel threatened about their power being diluted by people outside..."

(Interview National MIND staff member).
In contrast, several National MIND respondents described organisational changes which were designed to facilitate consumer involvement and shifts of power, such as the planning of a consumer advisory network and reforms in the electoral processes to Regional Councils and the Council of Management (124).

A few Westhill MIND respondents referred to the difficulties of consumers participating equally within the organisation with other members who had been involved in their care as professionals. In the words of one club member: "those [professionals] who lavish the time on MIND wield the hypodermic". A professional Executive Committee Officer commented:  

"..I think some professionals would feel inhibited by consumers [on the committee] because of the relationship between patient and doctor or social worker.."

(Interview. Westhill professional Executive Committee Officer).

In contrast, another social worker, who was coopted own Westhill MIND's Executive Committee said:

"..Club members are not in that power position [in relation to professionals], as at the Day Hospital, where you are the customer and people do things for you. Club members think the centre is for them..

(Interview. Westhill MIND professional Executive Committee member).
This chapter has included a review of the affect on consumer involvement of professionals' attitudes towards, and relationships with, clients. Professionals' initiatives to increase participation have been described in a variety of areas, but mental health workers have criticised for being agents of social control, and for perpetuating institutionalised and dehumanising regimes. Imbalances of power between professional and client with paternalism and invalidation of consumers' experiences, have been described.

From the early seventies, patients' rights movements have evolved to protest at bad conditions and patients' disempowerment. Some improvements in statutory mental health services have been described, but critics have commented that such changes are merely reformist, and fail to effect significant changes in power. Many MIND respondents stated that the attitudes of professional participants were particularly crucial in facilitating or hindering consumer involvement. Factors mentioned included professionals' encouragement of such participation, eg, by providing practical help and being aware of their own tendency to dominate. Openness to consumer views was also said to be important.

Whilst several authorities view power as an important component of participation, it is argued that this is problematic because it ignores the complex nature of both power and participation and some individual's wish for the latter, without concomitant increases in their power. This was true of many MIND members with consumer experience. Nevertheless, some
respondents referred to certain participants' unwillingness to accept shifts of power as hindering consumer involvement; or to organisational changes, which, they felt, would be likely to increase the power of consumers within MIND. Respondents also mentioned other factors associated with power, as facilitating or hindering consumer involvement, including consumers' feeling of empowerment related to skills and self esteem; and the structure of meetings, the language used, and opportunities to participate. These and other organisational factors are examined in the next chapter.
CHAPTER 12

ORGANISATIONAL FACTORS

This chapter examines the extent to which consumer involvement in MIND was affected by various organisational factors, including the following:

* 1. aims, history, and intended membership;

* 2. policies and resources;

* 3. organisational structure;

* 4. meetings and committees;

* 5. "image" of the organisation;

Each of these will be considered in turn.
AIMS, HISTORY AND INTENDED MEMBERSHIP

A number of differences were found between MIND and the other voluntary organisations which were studied:

1. AIMS From its inception in 1946, NAMH/MIND has always had a wide range of aims which have served the interests and needs, not only of consumers, but (to a lesser extent), laypeople and professionals. In contrast, Campaign Against Psychiatric Oppression (CAPO), Depressives Anonymous, the National Schizophrenia Fellowship and the Manic Depression Fellowship were all originally founded in order to provide support to consumers and/or their relatives with similar problems or experiences (1). Other objectives, such as public and professional education, were secondary, and developed out of the original aim of these organisations (2).

2. HISTORY Historically, MIND has developed from a beneficent organisation in which professional and lay participants, rather than people who identified themselves as consumers, have made decisions concerning the needs and interests of the latter (3). In the self help groups and CAPO, consumers and/or their relatives have always been entirely involved in such decisions (4).
3. **MEMBERSHIP**  

NAMH/MIND literature has always made it clear that membership is open to a wide range of consumers, laypeople and professionals (5). The literature of the other voluntary organisations indicated that their membership consisted mainly of consumers and/or relatives with shared problems or experiences (6).

Many respondents' views of the extent to which consumers should participate in MIND, and in the other voluntary organisations studied, appeared to be influenced by these factors, which will now be examined in more detail.

Previous reference has been made to a wide range of National MIND's aims, as reflected in respondents' views and aims and objectives listed in Annual Reports. The latter include those related to education and information for public and professionals (7). This diversity of aims was reflected in the mixed membership of MIND at the time of fieldwork, and in most respondents' views that professionals and laypeople, as well as consumers, should participate in the organisation. Whilst almost all respondents said they were in favour of increasing consumer involvement in MIND, few felt that it should be entirely run by consumers. The views of Eastvale and Westhill MIND participants, in relation to this, have already been considered (8). Table 12.1 indicates the views of National MIND respondents.
Some respondents pointed out that MIND should not be a consumer-run organisation because it was concerned with many issues, besides consumers' needs and rights. In the words of the National Director: "it is not only to consumers, but to the wider mental health movement that MIND seeks to be more accountable . ." (9). Another National MIND staff member commented:

"... I think the issue of mental health is broader than people who have been or are mentally ill. I don't think people who have used services should have a monopoly of views. I think [they have something to contribute, but] there is also a place for . . [other] people . ."

(Interview. National MIND staff member).

Several respondents felt that it was important that MIND encouraged the development of consumer movements and consumer-run organisations, whilst itself remaining an organisation in which a variety of participants was involved.
"... [MIND] needs a broad church because you're drawing on different skills and influences. I think it's very different from a consumer movement, which ought to operate alongside MIND..."

(Interview, Regional Director).

"... I think that consumers need to set up their own structures and organisations. I'm not at all sure that the best way for consumers' views to be represented is through MIND... To turn MIND into a consumer organisation may ultimately be to the detriment of consumers..."

"... Probably the best MIND could do... is to support the consumer movement's growth as a separate autonomous organisation..."

(Extracts from two interviews with an Assistant Director, National MIND).

Seven respondents referred to the importance of the participation of people other than consumers and several felt that it was necessary to maintain an appropriate balance of people with different roles and skills.

"... I think it is wrong to define a person as a criterion for working anywhere... It shouldn't rule out people who understand, without direct experience..."
"...I think it's wrong to think the only people with commitment to this cause have mental illness. Many of us who've been professional have high commitment...so it shouldn't disqualify us."

"...There should be a place for a variety of interests...It's detrimental to the organisation if none of these voices are heard..."

(Interviews, senior staff, National and Regional MIND).

A few respondents felt that consumer experience was not a sufficient qualification in itself for taking on a leadership role in MIND. "They should do it not just because they have had mental health problems, but because they are experienced and competent", said one National MIND volunteer. This respondent said she had had experience of a consumer-run voluntary organisation which had been unsuccessful. Another volunteer was very critical of Campaign Against Psychiatric Oppression (CAPO) for having what she described as a "dangerous unbalanced view", which, she felt, was to the detriment of other consumers. This respondent said that it was "not desirable or feasible" for MIND to be a consumer-run organisation "because you need a balanced view".
Compared with the other voluntary organisations which were studied, the aims and objectives of MIND were far more diverse, and with the possible exception of CAPO, greater in number (10). Whilst the aims of the self help groups and of CAPO eventually diversified, they started as organisations whose main purpose was to provide mutual support, and this is clear in their literature (11). In contrast, on its inception in 1946, the National Association for Mental Health inherited, from its three constituent organisations (12), a varied range of aims and activities concerned with professional and public, as well as consumer interests (13).

From their foundation, the literature of the three self help groups made it clear that they existed for people with specific types of problem or experience.

"... Everyone involved in Depressives Anonymous is either a present or a past sufferer from depressions for our fundamental belief is that depressives can help themselves and each other by the very fact of their shared affliction ..." (14).

"... The Fellowship consists of a rapidly growing number of sufferers and their relatives working together, particularly through local groups to lighten their burdens ..." (15).

CAPO's Manifesto also made clear the membership of this organisation:
".. Together with other oppressed groups, victims of psychiatry, through an organised Campaign Against Psychiatric Oppression, must take COLLECTIVE ACTION .. " (16)

Members of these organisations decided to open membership or meetings to interested professionals, but this was decided by consumers and/or their relatives, who set the terms of membership. (17). In MIND, it was the other way round. In its early years NAMH did not advertise itself as an organisation which welcomed the participation of consumers. Early Annual Reports contain few references to consumers or their relatives giving each other mutual support, or to their membership or participation in the organisation (18). In contrast, NAMH comments on the importance of attracting "legislators", so that the Association could exert influence on Central Government, and "professional people and others concerned for .. the prevention of problems arising from mental ill health" (19).

Unlike MIND, the other voluntary organisations which were studied were founded by consumers and/or relatives because of their personal experience and their wish to help others with similar difficulties. These individuals encouraged or enabled the participation of others. Thus, both the National Schizophrenia Fellowship and the Manic Depression Fellowship started after particular individuals referred to their personal experiences in national newspapers. The Fellowship of Depressives Anonymous began following a televised play by Nemone Lethbridge about her experience of depression, to which over three thousand people responded (20).
Both the Matthew Trust and CAPO were founded by people who experienced bad treatment whilst hospital inpatients, and who were determined to do something to improve the lot of others in similar positions (21).

In Chapter 4, reference was made to Gerard's classification of voluntary organisations, including those characterised by beneficence, reciprocity and solidarity (22). It is suggested that in their mutual support of people with similar problems or experiences, the self help groups showed features of reciprocity, whilst CAPO was characterised by solidarity, with members uniting in order to overthrow the mental health system (23). In all cases, consumers and/or their relatives were responsible for running the organisation. In contrast, in its early days, NAMH was a beneficent organisation, in which participants collectively did not, apparently, see themselves as having personal experience of mental health problems (or if they did, the organisation did not make explicit that this was why they were involved) (24). One respondent commented:

"... MIND never can one hundred per cent be consumer-based. It's trapped in its own history, and I'm not sure it ever should be a consumer organisation..."

(Interview. National MIND Assistant Director).

In the Annual Reports of the sixties and seventies, there are a few references to the involvement of consumers and relatives (25), but it was not until 1983 that National MIND specifically stated that it was keen to involve consumers in the organisation.
"... Internally, MIND must improve accountability to the consumer or patient. There is a clear need to reorganise MIND to voice more directly the views of those whom MIND claims to represent." (26).

"... With greater consumer involvement, MIND is on the threshold of developing a truly accountable approach to the needs of those labelled, diagnosed or treated as mentally ill." (27).

Previous reference has been made to Bender's view that, about this time, MIND had moved from a charity model "... towards an expertise model, whilst being attracted by the participation model." (28). This appeared to be the case at the time of fieldwork, when, as has been previously described, there was a stated interest in increasing consumer involvement in MIND, and the development of measures to achieve this (29). The next section describes the extent and nature of policies in effecting consumer involvement during the period of fieldwork.

POLICIES FOR CONSUMER INVOLVEMENT

Several authors indicate that successful participation depends on adequate conceptualisation (30), with clarity about the meaning, scope and limitations of participation in particular areas (31); the models, types and levels of participation which are appropriate (32); and who is to be involved (33). Certain writers on industrial organisations
conclude that participatory styles of management and working are appropriate in some occupations and not others; and that this depends on various factors, including the nature of tasks and the motivation and expertise of the workers (34).

The need for clearly stated objectives of participation has been described (35). Riley refers to the importance of specifying "the techniques by which community involvement is to be achieved . . . objectives and formal guidelines for community participation need to be developed carefully." (36). Lack of opportunities to participate has been described (37), whilst many authors comment that an absence of clear policies or methods to implement participation prevents its development (38). Thus Windle and Cibulka comment of citizen participation in community mental health centres that there were no "consistent institutional mechanisms for implementing the philosophy of citizen participation . . . disagreement over what . . . basic terms . . . mean . . . and over the values they imply . . ." (39). Leo Smith refers to "lack of uniformity and clarity of policy on participation" in local authority services in Islington (40); whilst Graycar comments of former Australian Government programmes: "the difficulty was that the real nature and ramifications of participation were not fully understood, nor were the objectives of the programme stated sufficiently clearly to make the participatory input truly meaningful" (41).

A study was made of policies and proposals for consumer involvement in National MIND, but one weakness of the research is that regional and
local respondents were not asked specifically about such policies and proposals at these levels of the organisation. Local and regional respondents rarely referred to these, with the exception of two Westhill MIND staff members who had presented proposals on consumer advocacy to the Executive Committee.

National MIND policies and proposals to increase consumer involvement during the period of fieldwork have previously been described in relation to changes in structure and accountability and in the electoral processes for regional councils and council of management; and through initiatives to increase accessibility of the organisation to women and people from black and minority ethnic groups; and to all consumers through the proposed Consumer Advisory Network (42). Attempts to involve consumers in national departments and regional offices did not appear to follow particular policies, with the exception of the Black and Ethnic Minority Team (43).

National and regional MIND respondents were asked “In what ways do you think consumer involvement in MIND can best be achieved?” (44). Table 12.2 shows the items mentioned by four or more respondents (45).
"VIEWS ON WAYS IN WHICH CONSUMER INVOLVEMENT IN MIND CAN BEST BE ACHIEVED?"

<table>
<thead>
<tr>
<th>Method of Involvement</th>
<th>No of Times Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through Local Associations</td>
<td>14</td>
</tr>
<tr>
<td>Consumer Advisory Network</td>
<td>13</td>
</tr>
<tr>
<td>Employment Opportunities in MIND</td>
<td>9</td>
</tr>
<tr>
<td>Staff training/changes in staff attitudes</td>
<td>6</td>
</tr>
<tr>
<td>Influence and involvement in policy-making/decision-making</td>
<td>6</td>
</tr>
<tr>
<td>Council of Management</td>
<td>5</td>
</tr>
<tr>
<td>Policy Committee</td>
<td>4</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>10</td>
</tr>
</tbody>
</table>

This question elicited one of the highest number of "don't know", responses from National MIND respondents. In addition, only two people mentioned work as a volunteer as a way in which consumer involvement could best be achieved, although this was one of the chief (and certainly, the most visible) ways in which consumers were involved in National MIND (46).

The lack of certainty about the best means to achieve consumer involvement is reflected in six Council of Management members' responses to the question: "Has Council of Management come to any decisions about how consumer involvement can best be achieved?" (47). Only one respondent said "Yes", with three Council of Management members replying in the negative, and two expressing uncertainty. Three of these respondents referred to the Consumer Advisory Network, with the respondent who had given an affirmative response commenting that Council had agreed to this being established.
A small number of National respondents were asked what they thought of consumer involvement in various areas (48). Almost all agreed with this in relation to the Consumer Advisory Network, Council of Management, Regional Councils and Executive Committees of Local Associations. Views on the benefits and problems of consumer involvement in these areas were mixed whilst four respondents felt that the Consumer Advisory Network would give consumers a voice and/or allow them to affect policy making, four other people felt that it would not have any real influence.

Problems related to power and representation were mentioned by some respondents. One volunteer said that he had found, from his experience of a Local Association and of the Mental Patients Union, that "patients' groups don't have any clout" (49). Another volunteer commented

"...the Local Associations with the most power are professional... conservative, pals with Health and Social Services. Consumer involvement must be as powerful, intellectually and politically."

(Interview: National MIND volunteer).

In contrast, the two respondents who expressed the most positive views about the Network felt that it would avoid the problem of tokenism. A Council of Management member commented that it would enable the participation of consumers who were "less skilled, less articulate, less confident" (50). A National MIND staff member felt that the Network was:
"...good... because it gives direct consumer input, and allows consumers to comment as an autonomous body. There's no worry about tokenism: They can make their own position clear, and judge where the organisation is failing them."

(Interview National MIND staff member).

Five respondents voiced concern that members of the Consumer Advisory Network would not be representative of other consumers. One volunteer was concerned that "people on it wouldn't give an idea what it was like to be an inarticulate user" (51), whilst a mental health professional on Council of Management said: "My main concern is we won't get the right people who know about mental disorder". This respondent expressed support for the idea of a Network, but feared that its members would express antipsychiatry views, which, he felt, would be unrepresentative of those of many consumers (52).

Three respondents feared that the Network would marginalise its participants. A member of Forum (53) said he questioned:

"...how much National MIND would listen to it... There may be too many voices to listen to...I would hope consumers would have [a voice in Regional Councils], without setting up something independent.".

(Interview Forum member).
Finally, one National MIND staff member very strongly disagreed with the establishment of the Consumer Advisory Network, stating that this would avoid facing the issue of enabling other MIND participants to be open about any personal experiences of mental health problems (54).

Most respondents felt that National MIND did not have clear objectives for consumer involvement (55). In referring to factors which facilitated or militated against consumer involvement, several respondents referred to policies and opportunities for such participation, or their lack. The commitment to consumer involvement of National MIND participants, particularly staff, was often mentioned. The National Director commented that it could be achieved by:

"...the appointment of staff who feel strongly about it. If there is the will, and if it comes from me, clearly there is some pressure to do something. I can create the ambience, the policy that we will involve consumers."

(Interview. National Director).

Whilst some respondents felt that staff and Council of Management saw the development of consumer involvement as a priority, a few staff members felt very strongly that, although there was a great deal of discussion about consumer involvement, there was no real commitment to it. One respondent, who felt particularly strongly, commented:
"...MIND doesn't want consumer involvement full stop. It wants to talk about it, have conferences about it... I think individuals want it: some, like [the National Director] very passionately, but the organisation doesn't. MIND has done very little about consumer involvement in the last forty years."

(Interview. Regional Director).

A few staff felt that MIND's organisational structure and culture inhibited consumer involvement, in that it was very difficult for participants to "come out", and share their own personal experiences of mental health problems (56). One respondent had written a policy paper proposing that consumer involvement could be facilitated if participants came out. However, this "got a very negative reaction. One person who'd suffered mental illness was positive about it. For others, it was a big threat" (57).

Two respondents commented on consumers' lack of opportunities for involvement in formal policy making "Unless you're a member of staff, you can't be represented in policy committee", said one staff member (58) whilst a Regional Director commented:

"...Certain members of Council of Management have, in the past, not been too welcoming to the idea of consumer representation on Council of Management, which I suppose then filters down to...other committees...".

(Interview. Regional Director).
EMPLOYMENT OF CONSUMERS

According to some authorities, the employment of present or former consumers can facilitate the participation, not only of those so employed, but of other consumers (59). Advantages are said to include similarities of experience and culture between the "consumer-employee" and those seeking help (60). Holland comments that in the USA, poor people were employed in poverty programmes in the belief that this would make the latter "more responsive to the needs of the poor" (61). Chamberlin refers to some advantages of mental health consumers choosing staff to run projects (62), but points out that the employment of some consumer participants as paid staff may result in less equality between members of patient-run alternatives (63).

Several MIND respondents commented that National MIND had an Equal Opportunities Policy, or employed people with personal experience of mental health problems, although two volunteers and several staff said that they felt there was a lack of opportunities for employment for consumers. One volunteer said:

"..I don't think [employment of volunteers] is encouraged... I've had to fight for everthing I've got out of MIND..",

(Interview National MIND volunteer).

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A few respondents said that working in National MIND required the ability to cope with stress, and that employment opportunities for consumers needed to take account of this. A few staff members suggested making changes in employment policies, so that there was more flexibility to suit the needs of employed consumers.

RESOURCES

The effective implementation of policies for participation depends on the presence or absence of various resources (64). These include adequate training (65), funding (66), physical factors such as adequate meeting space (67), and the time which participation involves (68).

Despite the emphasis in the literature, funding was rarely mentioned by MIND respondents as a factor which facilitated or hindered participation. Comments on physical factors are outlined elsewhere in this thesis (69). A few respondents described the costs of time that participation caused consumers and other people. Some consumers in Local Associations with high consumer involvement commented that lack of time was one reason why they did not want to be involved in regional and national levels of the organisation (70). An Assistant Director felt that providing adequate education for consumers could be time-consuming for MIND staff.

"...I know one or two staff members have had good ideas about how to involve consumers, but... have not been able to... spend the time..."

(Interview. Assistant Director, National MIND).
Some respondents referred to the importance of adequate training, particularly in relation to consumer involvement in committee meetings:

"...It's important that consumers know what is going on re agenda and minutes. People may need certain training to go from not knowing what to say to assertiveness...".

(Interview. Chairperson, Local Association with high consumer involvement).

"...You have to educate them about how the structure works...".

(Interview. Westhill MIND professional Executive Committee member).
In contrast, one respondent commented that her Local Association had tried to run committee meetings as informally as possible; and a Westhill staff member felt that the structure of meetings should adapt to the needs of consumers, and be accessible to them.

**ORGANISATIONAL STRUCTURE**

One important resource related to the facilitation of participation in an organisation is its structure. Some respondents referred to the importance of MIND's organisational structure as facilitating or hindering consumer involvement. Organisations' size (71), social structure ("particular patterns of role relationships" (72) and culture have been said to facilitate or hinder participation. Handy has identified four main cultures of work organisations (73), which allow for varying amounts of worker participation and autonomy depending on organisational goals (74).

Some authorities have differentiated between various types of structure for participation: e.g. in relation to their formality or informality (75). More formal structure, e.g. Boards, Committees, have been said to preclude the involvement of those people who lack the experience or skills to participation in them. Thus, Marris and Rein state of USA poverty programmes in the sixties: "The formal organisation through which the project authorised their decisions effectively precluded the effective participation of unsophisticated people" (76). A number of
writers indicate that bureaucracies, with their clearly defined roles, relationships and accountability, can hinder participation (77), although Jaques argues that these organisations can provide "requisite conditions for employee participation" (78).

Several writers comment on the importance of participatory structures which are sensitive to the needs and aptitudes of consumers (79). Jef Smith states that voluntary and statutory organisations need a diversity of structures to enable a variety of consumers to participate (80). In relation to political participation, Verba et al comment: "Lower status groups need a group-based process of mobilisation if they are to catch up with upper-status groups in terms of political activity." (81). Fowler states of consumer-run mental health groups: "how the groups organised themselves seemed as centrally important as any of the issues of campaigning" (82). Colom commented that adequate responses to mental health clients' complaints entail consumer "participation in the construction of a system" (83).

A number of authors criticise participatory structures which are decided by people in power on their own terms, and which consumers are unable to use (84). Caro states that in community mental health centres consumers have to "adapt their style".. [and] work within conventional procedural frameworks" (85). Leo Smith comments that:

".. the management system.. largely defines the issues on which consultation is to take place. ..People are rarely consulted on the issues they want to talk about." (86).
Several writers comment that certain organisations lack appropriate structures for consumer participation (87). These include social services, the law, voluntary organisations (88) and Local Government (89). Chamberlin refers to the absence of structures for mental health services in the U.S.A. (90) whilst Dyer comments of British mental health services in the mid eighties:

"...there are no clearly established rules or procedures of how to involve consumers. I am not aware of any authority which has recognised the involvement of consumers in the planning and provision of psychiatric services as a distinct management objective." (91).

Writing in 1991, Brandon comments that there is still little consumer participation in planning statutory services (92), although some Health Authorities have stated a commitment to consultation with users of mental health services and their families (93), and patients' councils, representing consumers' views, have been set up in at least five Health Authorities (94).

A number of authorities stress the importance of providing social environments which are conducive to the well being and the participation of users of mental health services (95). Several MIND respondents referred to the importance of providing social environments or "atmospheres" which promoted participation. The generally relaxed, informal, and often friendly environments in Eastvale MIND's Day Centre and in the social clubs in Westhill MIND have previously been described (96).
"The structure of informality facilitated consumer involvement. There are not many restrictions. It's fairly easy to complain because of the informality of it."

(Interview. Eastvale MIND Lay Executive Committee Member).

"As you say (97) the club is comfortable and relaxed, and conducive to people discussing ideas. It's very informal."

(Interview. Westhill MIND Club Member).

Similar factors were emphasised by participants in some of the Local Associations with high consumer involvement:

"the informality. The fact that you're not in hospital and people treat you like people, not patients."

"the atmosphere generally encourages things to start up."

(Interviews. Participants in Local Association with high consumer involvement).

Respondents in two Local Associations stressed the importance of an informal atmosphere, treating people as individuals, and enabling disagreements to be openly discussed.

"if people do not feel like doing something, they are encouraged to say so and to do something about it."

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"..we don't have a rule book. We give everybody the opportunity to have their say. We try to monitor disagreement and bring it into the open..".

(Interviews. Participants in Local Associations with high consumer involvement).

In one local association participation was said to be facilitated through the Executive Committee's decision that the social club should be run autonomously. Westhill MIND's social clubs enjoyed a similar situation, although a number of respondents felt that the Executive Committee were remote from club members (98).

A few respondents stressed that the involvement of consumers was facilitated when they were made welcome when they joined the Association. The importance of a democratic relationship between consumers and other participants was also mentioned.

"..an absence of barriers.. treating people on equal terms. [Staff's office] doors are never shut..".

(Interview. Staff member, Local Association with high consumer involvement).

Some respondents described the difficulty of attracting consumers to join their Local Association. One day centre member in Eastvale MIND had started a self help group for people with depression because she felt that the Association offered insufficient help with this problem (99).
The staff member of another Local Association said that she had expected that the high proportion of lay members on the Executive Committee would have facilitated consumer involvement, but that this did not happen because:

"...the group tends to be a clique .. which is difficult for new people to approach.. They are middle class, articulate, which would put off people not from that background."

(Interview.  Staff member, Local Association with high consumer involvement).

In contrast, one Local Association with high consumer involvement was said to fail to attract middle class people because its main project was in a rundown area of the town. The Chairperson of another Local Association said that it was difficult to make people aware that his organisation was "worth being involved in" (100).

In Westhill MIND, several respondents commented on the lack of equality between Executive Committee and Club members.(101).

"...The organisational structure is hierarchial. ..In a sense, everyone is answerable to the Executive .. club members are at the bottom of the scale.. There's unwritten roles."
Several respondents commented that there were more opportunities for consumer involvement in Local Associations, and/or that it was easier to achieve this at local level. Some people mentioned the possibility or desirability that consumer involvement would start in Local Associations, and later spread to regional and national levels of the organisation (102).

"..Local Associations, I think, involve consumers more than we do. It's difficult for us to involve them, other than through the Consumer Advisory Network because we don't have consumers with us, whereas Local Associations do."

"..A lot of things at local level you could get consumers involved in helping with, and none of these things exist at National level.. [e.g] drop-in services.. fund-raising activities.

(Interview. National MIND staff members).

One respondent felt that consumer involvement could best be achieved if National MIND took on some of the characteristics of a Local Association.

"..I think National MIND needs to become a Local Association as well .. a radical day centre .. run by consumers. Consumers doing.. the decorating, so it became a consumer organisation."

(Interview. National MIND staff member).

This respondent felt that such involvement would result in greater participation of consumers in National MIND concerns (103).
Although some National MIND staff felt that consumer involvement could more easily be achieved in Local Associations, the complexity of the latter were also seen by some respondents as hindering participation at local level.\(^{(104)}\) A club member in Westhill MIND commented that the idea of the Association's becoming a limited company was "pretty daunting", and a number of Executive Committee members commented on the skills needed to serve effectively on the Executive Committee \(^{(105)}\). The comparative complexity of Westhill MIND's aims and Executive Committee meetings, compared with those of Eastvale MIND, has previously been described \(^{(106)}\).

Two respondents in a Local Association with high consumer involvement indicated that the organisation's increasing complexity hindered the participation of people with consumer experience, other than the chairperson, who was an experienced businessman. Negotiating statutory funds for a building for the Association had required considerable financial skills which most members, apparently did not possess. Furthermore:

"...The committee have a responsibility for the building in legal matters. So things have to be well organised...that works against consumer involvement."

\(^{(Interview. Staff member, Local Association with high Consumer Involvement).}\)
These comments indicate the Local Association's accountability to its funding body as a factor which limited consumer involvement. A similar situation prevailed in Eastvale MIND, where officers of the Executive Committee stated that there needed to be limits to day centre members' participation for similar reasons. In Westhill MIND it was observed that a considerable range of complex legal, financial and building matters were discussed. It appeared to be difficult for anyone (consumers or non-consumers) to be involved in these matters because of the abstruse knowledge or expertise which seemed to be required (107).

**LEADERSHIP**

In such instances, leaders appeared to be needed to make decisions based on their specific expertise. Certain styles of leadership are said to facilitate or hinder participation. Maier described various characteristics of participative leadership, including "the capacity to share information; prevent dominant personalities from having disproportionate influence; solicit opinions, facts and feeling from reticent participants; [and] assist participants in communicating with one another" (108). Effective leaders in therapeutic communities have been described as democratic, willing to listen to others, and encouraging the sharing of decision making (109); but have also been described as charismatic and occasionally authoritarian, with the ability to push ahead with reforms, despite others' objections (110).
Reference has been made to the view of many respondents, especially in Westhill MIND, that professionals dominated some Executive Committees, in terms of both numbers and influence (111). Several participants, particularly in Westhill MIND, referred to the desirability of increasing consumer involvement, and decreasing professional involvement, in important decision making. A few respondents commented that it was not a good idea to have a mental health professional as chairperson because this could result in professional domination or consumer disempowerment (112), but there were few other references to leadership. Interestingly, a lay chairperson of a Local Association described how his "autocratic" leadership style had facilitated consumer involvement. In his experience, "...ground rules have to be dictatorially set down in relation to consumer involvement, because otherwise it drifts or dies, or becomes whimsically patronising." (113).

MEETINGS AND COMMITTEES

A number of authorities comment that meetings and committees can either facilitate or hinder participation, depending on their responsiveness and accessibility to consumers (114). The value of open or public meetings to give information or assess consumer views has been described (115), but several writers have described problems because the structure or content of meetings is intimidating to consumers, reinforces existing power structures or uses unfamiliar language or procedures (116). Finally, the importance of good communication as a facilitator has been
described (117), and this was referred to by MIND respondents. A few participants in headquarters mentioned communication difficulties, although one respondent felt that paradoxically, lack of communication facilitated consumer involvement:

"..the very looseness of MIND means we can actually get on with involving consumers .. without being stamped on by council of management.. Paradoxically, looseness and lack of communication allows this.."

(Interview. National MIND staff member).

Reference has already been made to Eastvale and Westhill MIND respondents' views on communication in their Local Associations (118). A number of Eastvale MIND respondents referred to the importance of day centre members being able to have a say and contribute ideas: e.g. through open meetings. The chairperson of a Local Association with high consumer involvement described regular meetings in a wine bar, which enabled consumers to meet local officials and politicians; whilst a respondent in another Local Association commented on the facilitation of a climate where all members were encouraged to say if they disagreed with anything in the organisation (119).

Whilst open meetings were viewed as facilitative of consumer involvement in Eastvale MIND, other respondents, particularly in Westhill MIND, referred to meetings' structure and complexity as hindering participation.
"..well, the structure doesn't lend itself [to consumer involvement] I don't see how it can. It's not just a social club where you can have a chat.. we're there to conduct business.." 

"..you feel you have to educate [consumers] about how the structure works..

(Interviews. Professional Executive Committee members, Westhill MIND).

Some respondents in Local Associations with high consumer involvement also referred to difficulties with meetings. Problems, each mentioned by one respondent, included difficulties in organising meeting; excessive rationality, with no opportunities to share feelings; and insufficient time for discussion, with frequent agenda topics which were unlikely to interest many consumers (120). A Westhill MIND staff member commented:

"..we're bureaucratic, formal. All these committees: secretary, agenda, and so on. I think committees could be far less formal and more accommodating.."

(Interview. Westhill MIND staff member).
Several MIND respondents pointed out that a committee structure made it difficult for certain people to participate, especially those who were inarticulate or unsure how to cope in committees. Three respondents felt that the system of nomination on to the Council of Management, with new members proposed by those already serving, militated against consumer involvement. It was partly for this reason that the National Director put forward proposals to change the electoral system onto Regional Councils and Council of Management, which were agreed by the latter and implemented the following year (121). Some respondents referred to Council of Management being dominated by professionals. "If [council] is predominantly run by professionals", said an Assistant Director, "it is not that keen having consumer involvement" (122).

A few respondents at Headquarters, and in Westhill MIND, questioned the commitment of some members to increase consumer involvement in their governing bodies. Resistance to change was occasionally mentioned as a hindering factor by National MIND respondents, and one staff member referred to Council of Management's "uncritical attitude to mental health services and to consumers' problems" (123). An officer of Westhill MIND Executive Committee commented: "I think the antipathy of the committee militates against consumer involvement.. It has to be a very competent outsider to do anything" (124). However, in interviews, the majority of Executive Committee members were in agreement with consumer involvement, though several expressed uncertainly about ways in which this could best be achieved (125).
Several Eastvale MIND respondents felt that the number of Executive Committee places which were open to day centre members itself facilitated consumer involvement (126). Towards the end of fieldwork, a number of subgroups was formed in Westhill MIND. These were concerned with issues such as public education and campaigning. Two respondents said that they felt that these would facilitate participation (127).

"..I think subgroups may help because people may be able to focus on one aspect, rather than take on board the whole lot."

(Interview. Executive Committee member, Westhill, MIND).

"..I think subgroups are good. Various people can be .. involved in any way they want."

(Interview Staff member, Westhill MIND).

Eastvale MIND had three subcommittees, in two of which all the members were day centre users. Although decisions in the fund raising subcommittee were made entirely by consumers, its chairperson complained that these were vetoed by a lay officer of the Executive Committee. This respondent also complained that decisions made by the Executive Committee were occasionally vetoed by the Day Centre Sub Committee, which included lay officers, but no consumer members (128).
"...There was no vote about the microwave [being bought], nobody on the Executive Committee had a say. ...With fund raising, we have to go through three committees to get anything done. ...we operate in a straitjacket.

(Interview, Consumer Executive Committee member, Eastvale MIND).

LANGUAGE IN MIND

Reference has previously been made (in Chapter 9) to some respondents' views that consumer involvement could be hindered by the particular language used in meetings and in National MIND literature. In addition, a number of Westhill MIND respondents commented that the style or language of Executive Committee meetings made it hard for consumers to participate.

"...I don't think the Executive Committee would explain clearly. With us, I think it's important in a step by step way so we're not intimidated."

(Interview, Westhill MIND club members).

"...Communication is one of the major problems people with psychiatric problems have. ... that's got to be looked at very carefully ... the expectation that people will understand minutes written in jargon."

(Interview, Westhill MIND Executive Club Member).
Training officers in National MIND described ways in which they had tried to make the themes of annual conferences relevant to consumers (129), and a poster was designed for the 1985 annual conference to indicate this. A Council of Management member felt that both Annual Conferences and Open MIND magazines provided platforms for some consumers. He commented that "the environment is all right for consumers who do have meeting skills", but considered that it was difficult for others to be involved (130).

**MIND's IMAGE**

This chapter will conclude with an examination of respondents' views of MIND's "image", as facilitating or hindering consumer involvement. Here, the term "image" is used in a similar sense to one of the meanings given in the Penguin English Dictionary: "the public's idea of what a political party, commercial product etc. is like" (131). It is suggested that MIND's image is reflected in its aims and whose interests it served; in its headquarter's location, building and address; the size of the organisation; the areas where local groups meet; its literature, meetings and conferences; and its membership, both rank and file and of its governing bodies.

Judy Wilson refers to the physical environment in which self help groups met (132) as one factor which affects membership and participation and this was mentioned by a few respondents. Reference has previously been made to the view of one participant that his Local Association failed to attract certain people, because it was situated in a rundown area (133).
Three National MIND respondents referred to such features as the organisation's size and the address, building and location of Headquarters as hindering consumer involvement. "Things to do with the image of MIND", commented a Regional Director, "the Harley Street address" (134). In contrast, a volunteer commented that he liked coming to Headquarters partly because of the part of London in which it was situated (135). A National MIND staff member commented:

"...where we are based... would make it hard for people to come into the building. They could find it quite awesome."

This comment was borne out by observation. National MIND was situated on the ground floor of a tall modern block of physicians' consulting rooms. During most of the period of fieldwork, the main door to MIND's offices was locked by a security device, and no one could enter without knowledge of the code. Callers were warmly welcomed by the receptionist, but the reception desk was not easy to find, and was closed at midday. People were occasionally observed in the foyer, trying to get into MIND (136).

One Regional Director commented that "the only thing that attracts [consumers] is the name "MIND". It's seen as a radical organisation..but the reality's different" (137). However, two National MIND staff said that consumers benefited from involvement in MIND because they "felt part of a movement for change", and that they felt they had an ally who would help with issues that concerned them. Several respondents mentioned consumers' favourable perceptions of MIND, and four volunteers said that they liked the friendly atmosphere in Headquarters (138).
This chapter has examined the extent to which consumer involvement was influenced by various organisational factors. Unlike the other voluntary organisations studied, MIND had started as a largely beneficent organisation, which had gradually sought to increase consumer involvement. MIND had a comparatively wide range of aims, and a more diverse membership, including professionals and laypeople, as well as consumers. In view of this, it is not surprising that the majority of respondents thought that the organisation should not be entirely consumer-run, and the advantages of other participants' contributions were described. The importance of skills and commitment, in addition to consumer experience was stressed.

The need for clear policies for consumer involvement has been stressed in the literature. MIND respondents expressed uncertainty about the best means to achieve such participation, with Local Associations and the proposed Consumer Advisory Network being mentioned most frequently. Views were mixed about the possible benefits and problems of various suggested measures to increase consumer involvement, and it was generally felt that objectives concerning this were unclear. Several respondents commented on the commitment of participants, particularly National MIND staff, to increasing consumer involvement, but a few people felt that this commitment did not extend beyond discussion.
Some respondents stressed the importance of Equal Opportunities Policies for consumers within MIND, or the need for particular resources, especially appropriate education, to facilitate consumer involvement.

Several authorities have highlighted the need for appropriate organisational structures for participation. MIND respondents referred to the importance of a social environment which was informal, relaxed, welcoming and democratic; and the provision of facilities which were accessible to a variety of consumers. Organisational complexity was seen as hindering consumer involvement: e.g. complicated aims, and functions such as negotiating finances, accountability to funding bodies, and work requiring specialist skills.

The structure of meetings and committees, and the language used, were also seen as important by some respondents. The need to provide adequate opportunities to express views was mentioned, and several people said that formal committee structure hindered consumer involvement. Finally, a few respondents mentioned factors related to MIND's "image" (such as the building used by Headquarters or some Local Associations) as facilitating or hindering consumer involvement.
CHAPTER 13

ACCOUNTABILITY, AIMS AND COMMUNICATION

So far, an examination has been made of the influence of particular groups of individuals, and of organisational factors and specific policies, on the development of consumer involvement (1). The next two chapters include an analysis of the relationship between different levels of MIND, with an examination of the extent to which national and regional participants influenced Local Associations in relation to consumer involvement and various aspects of their work. The influence of Local Associations on National and Regional MIND is also considered, in less detail.

The influence of MIND participants on other levels of the organisation was found to be affected by three factors:

* 1 Accountability within MIND, and relative autonomy of Local Associations.

* 2 The extent to which Local Associations were aware of, and agreed with, National and Regional MIND aims and perspectives.

* 3 The amount and quality of contact and communication between different levels of the organisation.
Each of these factors will be considered in turn. The extent to which different levels of an organisation exert influence on each other depends on what Handy describes as its culture:

"...[a set] of values and norms and beliefs - reflected in different structures and systems. In organisations there are deep-set beliefs about the way work should be organised, the way authority should be exercised, people rewarded, people controlled." (2).

According to Handy, organisational culture includes variations in the exercise of power and influence, and in the way decisions are made. "Influence is the process whereby A modifies the attitudes or behaviour of B. Power is that which enables him to do it" (3). Handy describes several types of power and influence, which vary, according to organisations' structure and functions, and which resemble some of those proposed by Max Weber (4). Thus, in a bureaucracy or role culture, power "comes as a result of the role or the position in the organisation" (5), and such power is usually legitimised by both managers and subordinates in the organisation. Other organisations are characterised by leaders with personal power or charisma, or leaders with expert power by virtue of specific knowledge or skills which are recognised by others (6).
ACCOUNTABILITY

In addition, organisations vary in the extent to which members are accountable to each other. Kramer states that there is a "lack of agreement about [the] meaning" of accountability (7) which, according to G.W. Jones exists when a person or institution has:

"..a task, function or role to perform, together with the capability to carry it out. There is also conferred some discretion and the liability to account for the performance of the duty..to act in conformity with the wishes and needs of those who conferred the authority."(8).

Definitions and descriptions of accountability in various professions emphasise the responsibility of professionals to patients and to society (9). For example, in nursing, midwifery and health visiting "accountability is an integral part of professional practice, since..the practitioner has to make judgments in a wide variety of circumstances, and be answerable for those judgements" (10). Elliott et al distinguish between contractual accountability and a "moral sense of answerability". The former entails fitting in with or doing what is required or predetermined by others. The latter is explaining and where necessary, justifying to others the decision that has been taken" (11).

Several writers state that the most clearly defined lines of authority and accountability occur in bureaucracies or role cultures, with their precisely defined rules and procedures and clear role specifications (12).
"The accountability of the manager for the work of his subordinate is of central importance in the manager–subordinate relationship. It is that accountability which makes the manager so dependent upon his subordinate. It determines the precise quantity of authority to which he is legitimately entitled in relation to his subordinate." (13).

In bureaucracies it is relatively easy for higher levels of the organisation to exert formal influence on lower levels. Thus, in a firm with a role culture, personnel in local branches are accountable for the implementation of policy directives to regional or area offices whilst the latter are accountable to the Head Office from which directives have come. The formal authority of each level to give orders to lower levels is seen as legitimate by subordinates, even if it is resented, and possibly subverted by the use of "negative power": "the ability to filter or distort information, instructions or regulations from one part of the organisation to another" (14).

Various writers' accounts of accountability in the ideal type of bureaucracy or role culture contrast with Rhodes' description of accountability in central-local government relations. Rhodes argues that conventional models of the latter are misleading because they ignore the very considerable variety and types of sub-central government, their ability to exert power and influence: e.g. through control of resources which central government does not have; and the limited ability of central government to exercise authority or influence over recalcitrant sub-central governments or to hold them accountable (15). Rhodes refers to the Layfield Report which argued that there is "an ambiguity and
confused relationship in which neither level of Government is clear about its responsibilities" (16).

Rhodes states that the attempts of Conservative governments of 1979 to 1987 to increase the accountability of local authorities to the centre were unsuccessful because of a failure to take into account the complexities of the relationships between different parts of the system (17). Evidence of this complexity has been found in a number of studies. Cousins refers to "the complexity and confusion of accountability" caused by a large number of bodies linking a London borough and the former Greater London Council (18). Elcock and Haywood found that accountability within the National Health Service involved considerable resistance, negotiation and discretion at district levels in the development of policies (19). In their account of community care for people with learning difficulties, Webb et al described various factors which affected the accountability of district and regional health authorities to the Secretary of State for Health and Social Services (20):

"..The relationships between centre - region - district cannot be characterised as between principal and agent; in reality, relationships are far more complex, with the formal hierarchial relationship mediated by the rules of the game" (21).

Compared with an ideal type of bureaucracy, with clear accountability, bounded by precise rules and procedures (22), Webb et al found that the implementation of certain policies was affected by shared understandings that there should be adequate consultation, that policies should be seen as "reasonable", and that latitude should be allowed in relation to certain policies (23).
Rhodes concludes that "confusion and ambiguity remain pre-eminent characteristics of inter government relations. The doctrines of ministerial accountability to parliament: belong to a simpler era" (24). He cites other authorities who have argued that recent Governments have failed to take into account the complex nature of accountability in inter-government relations (25): e.g, the distinction made by Heald between political, managerial and legal responsibility (26).

ACCOUNTABILITY WITHIN MIND

Data from interviewing and participant observation suggests that during the period of fieldwork, accountability within MIND had more in common with Rhodes' account of inter-government relations than with the ideal type of bureaucracy or role culture. Rhodes demonstrates that the relationships between central and sub-central units of Government are complex, and often ambiguous and multi-faceted (27). Similarly, the relationships between National/Regional MIND and Local Associations were found to be complicated, with most participants in various parts of the organisation having considerable autonomy. MIND's organisational structure has been described in Chapter 4 (28). The entire organisation was run by the Council of Management, led by the Chairperson, with lines of accountability down to the National Director and General Secretary, and thence, from the National Director to several Assistant and Regional Directors and their staff (29). A Management Team was responsible for the management of resources, whilst a policy committee made decisions and recommendations about policy matters (30).
Responses to questions in interviews suggested that in general, there were few differences in policy between Regional and National MIND, and clear lines of accountability of Regional Directors to the National Director. Regional staff were as involved as those at Headquarters in the Management Team and Policy committee.

"Regions are part of the National organisation. I'm a member of the management team, so am part of it. You couldn't separate the two."

(Interview. Regional Director).

Compared with regional offices, Local Associations had less direct involvement in National MIND. Six (one-third) of the ordinary members of Council of Management were Local Association participants (31). Other members of Local Associations could make recommendations to Council through a body called Forum, which consisted of representatives of Associations throughout England and Wales.

Membership of the Management Team and Policy committee was not open to Local Association members, unless (in the case of the policy committee), Council of Management nominated them. However, membership of working groups (which were concerned with specific mental health issues, and reported to Policy committee) was open to Local Associations, as well as to regional and national participants (32).
AUTONOMY

The extent to which National MIND policies influenced consumer involvement and other issues was affected by the autonomy of National and Regional staff and of Local Associations, which in the case of the former, co-existed with accountability to the National Director and Council of Management. Similarly, it has been found that, despite formal lines of accountability between different levels of government, some actors have enjoyed considerable freedom of decision making (33). For example, Webb et al have described ways in which the autonomy of psychiatrists adversely affected the implementation of Central Government policies for people with learning disabilities (34). Although the Secretary of State has the power to make policies, "clinical judgement remains a substantial obstacle to accountability" (35).

Participant observation and interview responses suggest that, despite formal lines of accountability, many MIND staff had considerable autonomy in making decisions related to their work, and (in some instances), marked influence on policy decisions made by Council of Management and Policy Committee. A number of respondents felt that Council of Management usually agreed to decisions being made by the Management Team and Policy Committee, rather than initiating policy themselves. An Assistant Director commented that Council was a "sounding board, rather than initiators" (36) whilst a member of this body commented:
"...Council of Management do a lot of rubber stamping. We have the power to throw things out. But it's all very sensible, and we nod agreement...".

(Interview. Council of Management Member).

This respondent seemed satisfied with this position, but another member of Council of Management felt that there was "...a bit of a conflict...a number of staff insist on things which are not in line with.. accepted policy" (37).

The autonomy of National and Regional staff co-existed with clear lines of accountability. Most respondents felt that, in general, National and Regional MIND had similar aims, although some people mentioned certain differences in function or emphasis (38). In contrast, accountability between national / regional and local levels was far from clear. Each Local Association was registered as a separate charity, whose members chose whether to have similar aims to National and Regional MIND, whether or not to affiliate to the former, and whether to stay affiliated. Indeed, at the time of fieldwork, there were several local associations of mental health which were non-affiliated, and entirely independent from National MIND (39).

Whilst National and Regional MIND sought to have influence over Local Associations, their power to do so was limited by the latter's autonomy as separate charities, and subsequent limitations in their accountability to other levels of the organisation. This situation is in contrast to
accountability within bureaucracies or role cultures in industry. For example, in a supermarket chain, it is relatively easy to ensure clear accountability between national and area offices and local branches, as the autonomy of the latter is limited by clearly defined rules, procedures and superordinate–subordinate relations (40). Furthermore, branches are not registered as separate companies to the national organisation, and cannot choose to disaffiliate.

Local Associations' relationship with National MIND more closely resembled the relationship of many local authorities to Central Government. Walker describes the strategies which the former use to assert their autonomy and weaken the influence of Whitehall (41). However, Local Authorities rarely leave the National–subnational system of Government; and it is difficult for them to be completely unaccountable to Central Government (42), which has the power to disband them (43).

The autonomy of Local Associations was often stressed in interviews and was reflected both in gaps in both Community Development Department records on Local Associations and in the knowledge of Associations of staff of the Region in which Eastvale MIND and Westhill MIND were situated (44).

The Chairperson and Secretary of Westhill MIND expressed particular disagreement with National and Regional MIND, and stressed the autonomy of their Association. When the Secretary was initially contacted about the research, it was explained that the local Regional Director had said he
was happy for Local Associations to be approached about the study. This initially caused the secretary considerable consternation (45). He stressed Westhill MIND's autonomy, and added "we don't have anything to do with National or Regional MIND. They're nothing to do with us" (46). The chairperson of the Association said, in relation to the regional office:

"...we have nothing to do with them. They do leave us alone. They find us prickly and well-organised. I have a lot of misgivings about National MIND, and what they stand for."

(Interview. Chairperson, Westhill MIND).

Other Westhill MIND respondents did not appear to feel as strongly about the Association's autonomy, and a few felt that there should be closer links with National and Regional MIND.

"...the Local Association ought to be more accountable. If National MIND is working out a policy which is national in scope e.g. if it's agreed National MIND has campaigning on drug use, I feel it's incumbent on the Local Association to participate, but it should depend on Local Associations being consulted about the matter and how it should be implemented."

(Interview. Officer of Executive Committee, Westhill, MIND).
"..I think Region have a lot to offer, and feel we should relate to them.. I think it's reasonable Region has some sort of accountability.. Equally, there should be accountability, the other way.."

(Interview. Member of Executive Committee, Westhill, MIND).

Two Westhill MIND staff members were perceived by other respondents as being more committed than the Executive Committee to the aims of National and Regional MIND (47). Both these staff members had done much to facilitate consumer involvement in the Local Association. One of them described her commitment to National policy to increase consumer involvement and other areas, and added:

"..I think we've been far too autonomous. I'd like to see more of us having interaction with National and Regional MIND.. much more closely aligned to them..

(Interview. Westhill MIND staff member).

Overall, Eastvale MIND Executive Committee members did not express strong agreement or disagreement with the aims of National and Regional MIND. There was a general feeling that the Association's autonomy was high. "Almost total" and "nearly complete" said two respondents. Two participants were very critical of what they saw as National and Regional MIND's lack of contact with Eastvale MIND, and the latter's lack of influence over the work of other levels of the organisation (48).
INFLUENCE AND RESOURCES

This section examines attempts of participants, particularly at headquarters and in regional offices, to influence consumer involvement at different levels of MIND. Here, the term influence refers to the process of making "others behave in a way in which they would not have behaved otherwise" (49). Rhodes refers to a range of resources which different levels of Government use to influence each other. These include authority, political legitimacy, financial, informational and organisational resources (50).

According to Rhodes, "authority refers to mandatory and discretionary right to carry out functions or services.. by statute or constitutional convention" (51). National MIND's influence on Local Associations was limited and did not extend to authority in these senses, or to political legitimacy. The financial resources it could offer to Associations were limited to concessional rates for MIND publications, courses and conferences, and a fund to which they could apply to finance particular projects (52). Organisational and informational resources included various mailings of information and copies of the Annual Report and a magazine for affiliated Local Associations, who also had access to the expertise and advice of National and Regional staff (53).

Whether the resources offered to Local Associations were a source of influence or not depended on their salience to local participants, and the extent to which they held National MIND in high esteem. Thus, in 1985
details of the proceedings of a workshop on consumer involvement were sent to all Local Associations (54). Data from observation and interviewing suggested that the extent to which this influenced Executive Committee members depended, in part, on their perception of the value and importance, both of national communications and of consumer involvement (55).

Rhodes refers to the interdependence of central and subcentral government, and the resources of the latter on which the centre depends. These include political legitimacy and informational and organisational resources (56). Similarly, in some ways there was interdependence of national and local levels of MIND. Annual Reports have stressed that MIND is a national movement affecting local people (57). It is suggested that National MIND’s credibility, and its ability to attract central government funding, depended, in part, on the willingness of Local Associations to affiliate. Rhodes describes ways in which subcentral governments have withdrawn their support for central government policies (58). Whilst Central Government has been able to use legal and other sources of power to ensure conformity (59), National MIND had relatively few such sources of power. Local Associations could exert some influence over National MIND because of their ability to disaffiliate and to refuse to support Headquarters.

The involvement of Local Associations in the organisation gave legitimacy to National MIND. For these reasons, it appeared to be in National MIND’s interests to take into account, at least to some extent, the views of local participants to ensure their support and commitment to National MIND causes.
Rhodes refers to organisational resources: "the possession of people, skills, land, building material and equipment" as means by which local authorities could influence central government (60). National MIND appeared to depend on Local Associations to provide local services for two reasons: firstly, to attract funding by central government at a time when the latter was keen to encourage the provision of many services by the voluntary sector (61). (National MIND itself provided almost no day or residential services) (62). Secondly, the provision of Local Association Services constituted examples of exemplary advocacy demonstrating examples of good mental health services which included consumer involvement. Such services assisted National MIND in its attempts to influence Central Government to provide similar statutory services (63).

In addition, National MIND relied on Local Associations for support of, and sometimes, involvement in, its campaigning activities. Local Secretaries were sent details of National MIND campaigns, sometimes with letters for Associations to send to the appropriate Minister or local MP's. Ways in which the campaigns unit involved Local Associations in the Tranx (minor tranquillisers) campaign have already been described (64).

Rhodes also refers to informational resources as a means by which subcentral governments influence central government: "the possession of data and to control over either their collection or their dissemination, or both" (65). National and Regional MIND relied on Local Associations to provide local information to legitimise and back up their campaigns and their attempts to influence central government. National and Regional
levels of the organisation also depended on Local Associations in their attempts to increase consumer involvement. Some respondents believed that such participation was most easily achieved at local level (66). An increase of consumer involvement in Council of Management and Regional Councils, as envisaged in the plans for changes in structure and accountability, depended, in part, on consumer involvement in local Executive Committees. National MIND also relied on Local Associations to adopt its Equal Opportunities Policies in relation to people of different ethnic groups and with particular disabilities (67). A few Local Association participants raised objections to this proposal, arguing that it had been imposed by National MIND (68).

PERSONAL INFLUENCE

Some organisational theorists have argued that the means available to people in positions of authority to influence subordinates depends on the nature of the organisation and tasks. Chell refers to "positive power": "the degree to which leaders are able to reward and punish, to recommend sanctions or otherwise to enforce compliance by subordinates. Thus if leaders have the power to give or withhold rewards then the more they can constructively use this aspect of their power the more influence they will have" (69).

Etzioni has argued that whilst organisations using coercive or utilitarian control can apply many material rewards and sanctions, those using normative control, including voluntary organisations, apply authority mainly through the personal influence of particular individuals (70). National MIND had few of the resources described by Rhodes to
influence consumer involvement in Local Associations. However, data from interviews suggested that it was the personal influence of particular National and Regional staff members which sometimes had an effect on such participation.

Chapter 14 includes an outline of ways in which National, and in particular, Regional MIND staff attempted to increase consumer involvement in Local Associations (71). Data collected from interviews suggests that the extent to which this was possible was influenced by a number of factors related to aims and communication. These included:

* 1. The extent to which Local Association members were aware of National/Regional MIND aims and policies.

* 2. The extent to which they agreed with these aims and policies, and were prepared to implement them locally.

* 3. The amount of identification with National/Regional MIND: a wish to be part of the National movement, or to be an entirely autonomous organisation with separate aims.

* 4. The amount of personal contact of Local Association members with National and Regional MIND participants.

* 5. The quality of communication from National and Regional levels.

Issues related to aims and communication will now be considered in turn.
AIMS AND GOALS

In bureaucratic organisations, all actors are expected to share much the same organisational goals (72), although several studies have found that, in practice, many participants have goals which are against those which are officially stated (73). Rhodes cites many instances of conflict between the goals and policies of central and subcentral governments. "Central decisions are not translated into action in any straightforward manner. On occasions, local authorities can simply reject central policy." (74). Referring to various authors, Rhodes gives examples of ways in which local authorities and other sub-central governments have been able to subvert, or fail to carry out central government policies on council housing (75), privatising services (76) and spending on local services (77).

In some industrial organisations accountability involves expectations that subordinates will perform certain tasks or share the aims and philosophies of the organisation as a whole (78). Some respondents' comments suggested that regional offices were expected to share National MIND's aims, but to interpret them in ways which were appropriate to local circumstances, and to act, in the words of one Regional Director, as:

"..a two-way function, a bridge between National MIND and Local Associations. ..we try to interpret [national policies] in a regional context."

(Interview. Regional Director).
Most national and regional respondents felt that Local Associations should have similar aims to National MIND, but many added qualifications.

**TABLE 13.1**

**RESPONDENTS' VIEWS ON WHETHER LOCAL ASSOCIATIONS SHOULD HAVE SIMILAR AIMS TO NATIONAL MIND**

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</tr>
<tr>
<td>Yes, with qualifications</td>
<td>13</td>
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<tr>
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</tr>
<tr>
<td>No, with qualifications</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Don't know</td>
<td>2</td>
</tr>
</tbody>
</table>

n 23

Seven respondents felt that Local Associations should share National MIND basic aims or principles, but with some differences according to local need.

"...they should have broadly similar aims by virtue of being affiliated. Some differences [are appropriate]. It's difficult to ask volunteers to adopt radical policies..

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"...National MIND can influence larger issues like.. central government policies, which Local Associations can't. Local Associations can influence local bodies...".

(Interviews. National MIND staff).

Beliefs that National MIND and Local Associations should have similar aims appeared to be contradicted by respondents' comments on the main aims of the level of MIND in which they were principally involved (79). Whilst service provision was strongly stressed by Eastvale and Westhill MIND Executive Committee members, respondents at Headquarters mentioned influencing statutory services, campaigning and legal issues far more frequently. These were hardly ever mentioned as aims of the Local Associations (80). Furthermore, only one respondent felt that national and local aims were unequivocally similar. Other participants felt that there were differences in aims, or that it depended on the Local Association (81). Several respondents said that some local MIND participants did not find National and/or Regional MIND aims of any salience (82).

A wide range of views about National and Regional MIND aims was expressed by Eastvale and Westhill MIND Executive Committee members; and Committees, as opposed to individual members, did not appear to hold many cohesive views. Several respondents spontaneously mentioned their agreement or disagreement with National/Regional MIND aims. Interestingly, a number of these participants also indicated a lack of knowledge of these aims.
Nevertheless, this did not preclude some of them from holding strong views (83). A Regional Development Officer said that he had found, from circulating a questionnaire to Local Association members in one region that "sixty per cent had little idea what National MIND was about", and many felt that they had insufficient knowledge of the work of Headquarters (84).

Some respondents stressed that there were quite similar basic principal or general aims at different levels of the organisation, such as concern for consumers' needs; but referred to wide differences in specific aims, both between national and local level, and between different Local Associations. Many respondents stressed that the latter tended to meet consumer needs through service provision, whilst National MIND concentrated on campaigning. Links with Headquarters were said to sometimes cause difficulties for those Associations who were trying to establish relationships with, and assure funding from, local statutory authorities.

"...I think that a very large number of local groups would prefer just to be service providers without the campaign work. A number... have objected to National work, especially if this is critical of their Health Authority or hospital staff...".

(Interview. National MIND Staff member).
"...Where the conflict occurs is in issues .. supporting statutory services. The local associations cover gaps within those services.. they don't really support aims .. of National MIND over the need for change..".

(Interview. Forum member).

Many respondents' comments suggested that there were discrepancies between national/regional and local views about how the needs of consumers could best be met. A few Eastvale and Westhill MIND participants disagreed particularly with National and Regional MIND aims. The especially strong views of the chairperson and secretary of Westhill MIND have previously been referred to (85). A consumer member of Eastvale MIND's Executive Committee commented:

"..most of the people in authority round here don't like us because ..they think we're supporting National MIND campaigns which we don't agree with. National MIND gives us a bad name at times.. we have objectives completely different to National MIND. We're interested in our doings, involved enough in that. .. Even though we're affiliated, we don't have to agree with them..".

(Interview. Consumer member of Executive Committee, Eastvale MIND).
Another member of Eastvale MIND's Executive Committee commented:

"..I think one of the tensions is that National MIND does political campaigning .. and the Local Association more service delivery. National MIND's campaigning could .. undermine work at a local level, so Local Associations sometimes dissociate themselves from National MIND..".

(Interview. Executive Committee member, Eastvale MIND).

In summary, interview responses suggested that most National and Regional MIND participants both felt that Local Associations should share broadly similar aims with Headquarters, and were aware of differences in aims in practice. Some Local Associations respondents said that they did not know the aims of National MIND, and/or expressed (sometimes strong) disagreement with the aims of other levels of the organisation. These factors suggest that National and Regional policies and views on consumer involvement were likely to have little influence on Eastvale and Westhill MIND, and perhaps, other local Associations (86).

COMMUNICATION AND CONTACT

The extent to which consumer involvement in Local Associations was influenced by national and regional policies also depended, in part, on the extent of communication between different levels of the organisation. "Neither the nature of the communicator nor the communication will have any effect if individuals are not prepared to expose themselves to new information" (87).
Fifteen National MIND staff were asked about the extent to which they or their department/unit communicated with Local Associations (88). There was considerable variation, with about half stating that this was "nil" or "slight" (89).

The Community Development Department, and its Local Associations Co-ordinator, in particular, sent various communications to Associations from Council of Management and National MIND staff. The most frequent communications from the latter concerned the provision of information or help to Local Association members, training matters, and the referral of people in distress who had contacted Headquarters (90). Two respondents said that they had contacted Local Associations about matters concerning consumer involvement. The Local Associations Co-ordinator informed them of a workshop on this topic, and on other matters concerning participation. Two assistant directors had communicated with Local Associations to invite them to take part in campaigns and to seek their views. A few respondents had used Local Associations newsletters, other publications and forum meetings to bring issues to the attention of local participants.

Several respondents, especially in National MIND and Westhill MIND referred to communication problems between national and local levels. Comments included "Local Associations are not always informed", "Local Associations have not been consulted enough in the past", and "most Local Associations agree [with National policy] .. but would like communication earlier." However, a Regional Development Officer commented that some Local Associations felt that they received too much information from Headquarters. Both the Local Associations Coordinator and a member of
Forum commented that local participants sometimes complained that National MIND had not communicated about a particular issue, when they had, in fact, received information about it in mailings from Headquarters (91). This is reminiscent of Handy's comment that distortion of communication within work organisations has been found to be caused not only by "omission or distortion by the sender", but "perceptual bias by the receiver. We only... perceive what we are ready to receive." (92).

Some respondents felt that poor communication was a reason for National MIND's limited influence on Local Associations. A few people said that when there was congruence between national and local aims this was coincidental, rather than because of staff influence or good communication.

"...when National policies and Local Associations agree, this is more because of Associations' awareness of the issues... than because of communication from Harley Street..."

(Interview. National MIND staff member).

COMMUNICATION FROM REGIONAL STAFF

Interview responses suggested that communication from regional offices to Local Associations appeared to depend on at least three factors:

* 1. the extent to which Regional Development Officers (93) saw work with Local Associations as important;
2. the extent to which Local Associations invited, and/or initiated contact by Regional MIND staff;

3. the amount of time that regional staff had available to contact Local Associations.

Three Regional Development Officers stressed the importance, in their work, of providing a service to Local Associations, but another two saw this as a relatively small part of their role. Some regional respondents indicated that Associations varied in the extent to which they were prepared to communicate with Regional and National MIND (94). One Regional Development Officer felt that the extent to which Local Associations communicated with regional staff affected the former's influence on regional policies (95). Insufficient time was another factor which made communication difficult. The Director of one Region said he would have liked to increase communication from the regional office to Local Associations, but there was "a lack of people to organise it." (96).

Respondents indicated that Regional MIND staff communicated on a wide range of topics, including issues related to consumer involvement, which were mentioned by three people (97).

In preliminary fieldwork, five respondents (two at regional and three at local level) were asked to rate communication from "Albion" Region (in which Eastvale and Westhill MIND were situated) on seven topics, including consumer involvement (98). Four respondents rated most items, including consumer involvement, as "slight" (99), but a Westhill MIND staff member rated all seven topics as "marked" or "very considerable". He commented that, with regional staff, consumer involvement was:
"...discussed a lot, but [we're] no wiser about it. As issues for discussion, bringing workers together, presenting a paper... with the limited staff they're got, it's very good...".

(Interview. Staff member, Westhill MIND).

However, this respondent felt that there was little communication about consumer involvement, compared with other topics, from his Local Association to National and Regional MIND (100).

Interview responses indicated that the other regional offices varied in the amount of communications to Local Associations which concerned consumer involvement. Staff in two other regions said that little of their communications to Associations was related to this.

"...It's minor, compared with other topics: less than between the regions. It's left to National MIND...".

(Interview. Regional Development Officer).

Staff in the other established Regions (101) said that some communication with Local Associations concerned consumer involvement. This was most marked in "Region C", whose staff had circulated Local Associations with a questionnaire to assess the extent of consumer involvement, and held a meeting about this with the new Regional Council (102).
Officers in other regions said that they often discussed consumer involvement with developing and established Local Associations. The work of staff in facilitating participation is discussed in Chapter 14 (103).

Eleven out of nineteen Eastvale and Westhill MIND Executive Committee respondents said they had had some contact with other levels of the organisation, but this was only "slight" for all but four of them (104). For most respondents, contact consisted of correspondence about practical matters, asking for information, and attending a National MIND Annual Conference or course. Both Local Associations had a Forum member, and an Officer of Eastvale MIND was a member of the local Regional Advisory Committee. In Westhill MIND, one respondent had been a Council of Management member and an observer at the Regional Advisory Committee several years before the period of fieldwork. Another Westhill MIND Executive Committee member was occasionally asked to speak at conferences run by the local regional office (105).

Overall, Executive Committee members appeared to have slightly more contact with Regional, compared with National MIND, and interview responses suggest that this was greater for Eastvale MIND. Some respondents had met members of regional staff, and a few had visited the regional office. Six Executive Committee members in the two Associations referred to problems in communication with National MIND. Two of these respondents reported similar problems with the regional office, although others said they had found contact with regional staff helpful (106).
In contrast, the Chairperson and Secretary of Westhill MIND both expressed particular concern about the lack of communication from Headquarters, and to a lesser extent, the regional office. The chairperson referred to "almost complete dispute between the Local Association and National MIND, since National MIND started" (107). He commented on disagreements about Headquarter's intervention in a Westhill MIND project and on a National MIND policy document:

"...We almost thought of disaffiliating. ... It seemed as if National MIND was putting ... responsibility on Local Associations to carry out National MIND policy, without acting in a democratic way. Decisions were made mainly by national... and regional staff, with little say from Local Associations. ...We wrote back, said we were not prepared to accept it...".

(Interview. Chairperson, Westhill MIND).

However, the concern of the Chairperson and Secretary about lack of communication from National MIND was voiced to a lesser extent, or not at all, by other Westhill MIND respondents.

"...I think National MIND could communicate [more]...but I think they have a lot to offer, and feel we should relate to them...".

(Interview. Westhill MIND Executive Committee member).
There is a lot of resentment [about National MIND's lack of consultation], but I think the Executive Committee allows this to cloud the issue.

(Interview. Westhill MIND staff member).

Whilst two Westhill MIND Officers expressed concern at what they saw as National and Regional MIND's "interference", three Eastvale MIND Executive Committee members felt that these levels of the organisation should play a more directive role in the Local Association.

"...they ought to get to know their Local Associations better than they do, have more contact with them: visit or... phone... to see if Local Associations are all right...".

"...they should... spend more time from regional level... guide along the right lines, provide back-up training for Local Association members... if an Association's got a problem, Region should sort it out...".

(Interviews. Eastvale MIND Executive Committee members).

Finally, a few regional respondents indicated that there was considerable variation in the extent to which Local Associations made initial contacts with regional offices. The relationship of Associations with regional staff, and the former's degree of self sufficiency were mentioned as factors influencing this:
"...Some would die rather than communicate... There's good communication with some, appalling with others...".

(Interview. Regional Development Officer).

Requests for help were said to be the most frequent reason for Local Associations to contact regional staff: e.g. in relation to setting up new projects and fund-raising, and support from staff employed by Local Associations. One Regional Development Officer said that people with consumer experience often contacted her:

"...If they feel the Group is going off course, telling me I need to change things, or as a friend of mentally ill people. I may see... the chairperson of a Local Association in that capacity, but give a lot of support to her because she is a consumer...".

SUMMARY AND CONCLUSION

This chapter has examined accountability within MIND, the aims of different levels, and communication between them. These factors affected the extent to which National, Regional and Local MIND could influence consumer involvement elsewhere in the organisation.

Local Associations were found to have considerable autonomy, and their relationship with National/Regional MIND more closely resembled that of central - subcentral governments described by Rhodes than relationships within a bureaucracy. National and Regional MIND staff also had quite considerable autonomy, despite their accountability to management.
Resources which National/Regional MIND could use to influence Local Associations were limited because of the latter's autonomy. Moreover, Headquarters appeared to need Local Associations for reasons of credibility and to attract central government funding; and the provision at local level of high quality service provision (exemplary advocacy), and of local information to legitimise National MIND's campaigns and lobbying of central government.

National/Regional MIND's main resource to influence Local Associations was personal influence, but the effect of this depended on local participants' relationships and communication with staff at other levels; and the extent to which Local Associations agreed with National/Regional MIND aims, and saw them as salient. There was considerable variation, in these respects, between Local Associations. Most National MIND respondents felt that the latter should share aims with the rest of the organisation, but many participants in Eastvale and Westhill MIND were unaware of the aims of Headquarters. In addition, there were some clashes of aims and perspectives between different levels, particularly in relation to National MIND campaigns and Local Association members' desire to get on well with statutory authorities, for whom they provided services and received funding.

Finally, several respondents reported problems in communication between national and local levels. This was said by some to contribute to National MIND's limited influence on Local Associations. Communication from regional staff to local participants, and vice versa varied. Most Eastvale and Westhill MIND Executive Committee members had little or no contact with other levels of the organisation.
CHAPTER 14

STAFF'S PERSONAL INFLUENCE

This chapter includes an examination of the extent to which national, regional and local MIND participation exerted influence on other levels of the organisation, in relation to consumer involvement and other matters. Particular reference is made to the role of National and Regional MIND staff in facilitating consumer involvement in Local Associations.

THE INFLUENCE OF NATIONAL MIND ON LOCAL ASSOCIATIONS.

National MIND respondents were asked to estimate the extent of the influence of Headquarters on Local Associations (Table 14.1) (1).

TABLE 14.1

Q12.32a. ESTIMATES OF EXTENT NATIONAL MIND INFLUENCED LOCAL ASSOCIATIONS

<table>
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<td>Marked to considerable</td>
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</tr>
<tr>
<td>Fair</td>
<td>1</td>
</tr>
<tr>
<td>Varies</td>
<td>6</td>
</tr>
<tr>
<td>Slight</td>
<td>9</td>
</tr>
<tr>
<td>Nil</td>
<td>0</td>
</tr>
<tr>
<td>Mixed response</td>
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</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
<tr>
<td>Don't Know</td>
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The most frequent responses were "slight" and comments that the extent of National MIND influence varied considerably between different Local Associations. Several respondents indicated that this was limited in the case of many Local Associations because they were uninterested in National MIND issues (2). Some individuals referred to the lack of salience of National MIND to some local participants: e.g. because of insufficient time to familiarise themselves with the policies of Headquarters (3). Reference has previously been made to some Local Association members' lack of knowledge of, or interest in, National/Regional MIND aims; and in some instances, the difficulties caused by National MIND campaigning to Local Associations who provided services for, and/or received funding from, local statutory authorities (4).

Interview responses suggested that overall, Local Associations which were more recently established were more likely, compared with older Associations, to be influenced by National or Regional MIND policies, partly because Regional staff had been involved in their development to a greater extent. Some respondents indicated that members of some older Associations distanced themselves from Headquarters or their Regional office by refusing to include "MIND" in the name of their organisation, and using "Association for Mental Health", instead. During the period of fieldwork, affiliation packages stated that Local Associations founded in or after 1986 had to include the word "MIND" in their names in order to be accepted for full affiliation (5).

"...National MIND generally affects MIND Local Associations more than Associations for Mental Health...If they are more consumer-orientated...they'll be more affected...".

(Interview. Forum member).
Some respondents referred to poor communication between National MIND and Local Associations as a reason for the former's lack of influence (6), whilst others mentioned Local Associations' autonomy, and their differences in aims and philosophies to Headquarters (7).

"..Local Associations are autonomous: registered as separate charities..It would be difficult to say to them: "These are our policies. If you do not agree, you are not part of us.""

(Interview. Assistant Director,) National MIND).

"..I don't think [MIND has any influence over Local Associations] except, possibly, the Tranquillisers Campaign (8). ..There's a non-existent relationship between National MIND and London Local Associations.."

(Interview. National MIND staff member).

Few respondents felt that the proposed changes in structure and accountability would result in more than a slight increase in National MIND's influence on Local Associations (Table 14.2) (9).
Respondents voiced a number of reservations. One National MIND staff member felt that the changes would "enable National MIND to have more of a check on Local Associations, and would increase their influence on certain areas such as Equal Opportunities"; but that "otherwise it was not clearly spelt out". Several respondents said they felt that National MIND would have little influence as a result of the proposed changes (10).

Two respondents felt that improved communication between different levels would result, although several people felt that differences in aims or perspectives could continue to affect National MIND's influence on Local Associations. However, a Regional Director hoped that the proposed changes would enable Local Associations to understand issues which concerned Headquarters. Another Regional Director added that the lack of accountability of Local Associations would not be improved. "Local MIND will still be able to drag National MIND into disrepute," (11).
Two respondents welcomed the new structure because they felt it would exert essential control on Local Associations: e.g. in relation to requirements for affiliation, equal opportunities policies, membership records and voting at Annual General Meetings. Other participants were less happy with the proposed increases in accountability. The chairpersons of both Eastvale and Westhill MIND expressed concern.

"..Obviously, I was slightly worried that National MIND would influence Local Associations more. Are they going to expect more of us?..".

(Interview. Chairperson, Eastvale MIND).

A Council of Management member, who was a Local Association participant, commented that, at local level:

"..We want to be left alone. National MIND has too much influence..I think Local Associations have got to be left alone to deal with local needs.".

(Interview. Council of Management member).

An attempt was made to assess the influence of National and Regional MIND on consumer involvement in Local Associations.
Chapter 6 included a description of ways in which National MIND participants facilitated consumer involvement throughout the organisation, including the proposed changes in structure and accountability, the establishment of the Consumer Advisory Network; and the holding of Workshops for Local Associations on consumer involvement, and Annual Conferences which encouraged such participation, and had this as a theme.

An examination was made of respondents' views of the reasons for the development of ideas to increase consumer involvement at different levels of the organisation. Data from interviews and participant observation suggested that the influence of National and Regional MIND staff was of central importance. Many instances were found of initiatives for consumer involvement which had come from these participants, and later been agreed by Council of Management and Forum (12).

Reference has already been made to attempts to seek consumers' views and otherwise involve them in decision making at National and Regional levels of the organisation (13). Impetus for the Consumer Advisory Network, the Bristol Workshop on Consumer Involvement (held in May, 1985), and concern to cover consumer issues and facilitate consumer involvement in the 1985 World Congress on Mental Health and Annual Conference, appears to have come mainly from National MIND staff. Ideas for increasing consumer involvement were mooted at a staff policy conference in 1984, with proposals for the Consumer Advisory Network and consumer involvement in Annual Conferences originating from particular staff members. During the period of fieldwork, staff in a number of National MIND departments had initiated consumer involvement. The work of various departments in relation to this has been described in Chapter 6 (14). Here, initiatives of members of the Black and
Ethnic Minority Team and of the Training and Education Department will be briefly outlined.

Six respondents referred to contact with Local Associations through training events. The Black and Ethnic Minority Team, which started in May, 1985, as part of the Community Development Department, acted as a resource for Local Associations, advising them how to make their organisations and services more accessible to members of black and minority ethnic groups, and running workshops on this topic. Increased involvement of such people with consumer experience could obviously not be facilitated until more of them joined Local Associations. Members of the Black and Ethnic Minority Team aimed to directly influence Local Associations, enabling them to be aware of institutionalised racism in their organisations.

"...We try to get Local Associations to make services more accessible to members of the black and minority ethnic community. We try to get Local Associations to adopt Equal Opportunities policy, and monitor this... and have suggested Equal Opportunities policy as part of affiliation packages [for Local Associations]... [We aim to] get blacks in the managerial structure of Local Associations...".

(Interview. Staff Member, Black and Ethnic Minority Team, National MIND).

Members of this Team had "offered support, guidance and advice" concerning the implementation of these policies. For example, they had made suggestions to members of a Local Association, in an area with large Asian
populations, about ways of involving members of these groups in a non-paternalistic way (15).

Three members of the Training and Education Department had been involved in Local Association training, although this was a small part of their work. Two of these respondents described how they had used this contact to facilitate consumer involvement at local level.

"..I said to Midchester MIND, "bring people involved in using the project" [to a training event.] They looked taken aback, but did so..

".. I get things referred to me by Local Associations: e.g. about psychiatric hospital closure. I ask them: "Have you talked to consumers? .. Is it what consumers want?". (Interviews. Training and Education Department staff, National MIND).

One staff member in the Training and Education Department described how ideas for consumer involvement in the Annual Conference had come from herself and a colleague. When asked if this had been readily accepted, she said: "Oh yes. I think in MIND it's like being against sin. No one is going to argue."

However, this respondent expressed surprise that her ideas for the 1985 Annual Conference, including free admission for users of mental health services, were so readily accepted by Council of Management. A large
number of people with consumer experience spoke at this conference or ran sub-plenary sessions. They were from a variety of organisations, including three Local Associations, all of which were amongst the sample of Associations with high consumer involvement. Although participation in the conference appeared to be initiated by National MIND staff, the content of sessions and addresses seems to have been decided by consumers in local organisations (16).

INFLUENCING CONSUMER INVOLVEMENT IN EXECUTIVE COMMITTEES

According to the Local Associations Co-ordinator, National MIND's attempts to influence consumer involvement in local Executive Committees originated with the first Assistant Director of the Community Development Department during the seventies. She had suggested that all Executive Committees have a balance of consumers, professionals and laypeople. Subsequently, this was proposed by both Forum and Regional Development Officers (17).

"Regional Development Officers working with new groups would always ensure .. a well balanced Executive Committee before recommending affiliation. .. If the Local Association insists on affiliation before the Regional Development Officer feels they're ready, she says: "It's too professionally dominated. I'm working with them to get more consumers and laypeople [on the committee]." Then Forum reject the application, or provide affiliation if [this is] fulfilled..".

(Interview. Local Associations Co-ordinator, National MIND).
Interview responses suggested that, once Local Associations were accepted for affiliation, it was difficult for anyone to ensure that their committees maintained the "right balance". This appeared to be at least partly because of their autonomy. The Local Associations Co-ordinator pointed out that some Associations had Executive Committees consisting largely of "non-consumers" after they had become affiliated; and that, in terms of acceptance for affiliation, "consumers" could include relatives of people with mental health problems. In preliminary fieldwork in "Albion" Region, of nine Local Associations chosen for study, only one (Eastvale MIND) had an Executive Committee with more than one individual with consumer experience.

Several National and Regional MIND staff voiced approval of particular Local Associations with high consumer involvement. Views were frequently expressed that local "consumer involvement was a "good thing", and that too much professional involvement was a "bad thing". The importance of Executive Committees having a "balanced membership" was also stressed, with many respondents commenting that not all members should be consumers (18). In an open meeting of National MIND the Chairperson of Council of Management referred to the importance of consumer involvement in Local Associations (19).

THE INFLUENCE OF REGIONAL MIND ON LOCAL ASSOCIATIONS

The influence of Regional MIND staff on Local Associations will be examined firstly in relation to examples of ways in which staff in Albion Region attempted to influence Local Associations in general; and secondly, in relation to the development of consumer involvement.
Albion Region staff found it difficult to influence Local Associations. Communication between Regional Development Officers and each Local Association varied, partly because of the lack of accountability. Local participants could choose whether or not to communicate with regional staff or to respond to the latter's attempts to communicate with them. This meant that they were in the "silly position of not being one hundred per cent sure of what Local Associations were doing" (20), with some uncertainty about the nature of Local Associations' projects and the problems which they encountered. The Regional Development Officer said that she sometimes asked for views and information, but received little response at times.

"...I try to get feedback... ask for comments, which is unproductive. I ask people what they are doing about Minor Tranquillisers: [a project initiated by National MIND in response to expressed consumer need]. Probably two of twenty two groups reply...".

(Interview. Regional Development Officer).

The lack of accountability made it difficult for this respondent to exert influence, other than through personal influence and developing relationships with Local Associations.
"..Local Associations are not accountable. Our hands are tied .. Region may be able to influence them by striking up a relationship with members of the Executive Committee. It's quite difficult at times because National MIND (can be) .. provocative, but Local Associations find that threatening. It can be difficult to bridge over that..".

(Interview. Regional Development Officer).

The Regional Director felt that Local Associations should be more accountable to Regional and National MIND, and despite the problems of ensuring this, had set objective - setting exercises for two Local Associations who, in the opinion of regional staff, were not functioning well. Some Local Associations had been unhappy about such evaluation. The Regional Development Officer's dilemma was how to exert influence on Local Associations which would both bring about change, and be acceptable to them. Her method was a covert one.

"..There's a problem with the Regional Director who has gone in and said "let's look at what you are doing" .. Local Associations have felt quite threatened by it: very defensive, understandably. I try to get people to do what you want them to, without their realising it..".

(Interview. Regional Development Officer).

The Regional Director suggested that influencing Local Associations was:
"...down to force of personality. e.g. Midtown MIND give me authority and status. It’s down to individual relationships...".

(Interview. Regional Director).

This respondent felt that MIND should be “decentralised”, with Regions having “almost complete autonomy from National MIND”, and with branches, instead of autonomous Local Associations, responsible to the regional office. He said that most Local Associations would not agree with such a suggestion, which was not put forward by other respondents and felt strongly that Local Associations should:

"...strongly identify with the MIND organisation. Groups get up my nose who don’t do so. I like Local Associations to use the MIND name. When Southfield MIND don’t like what we do .. they call themselves Southfield Association of Mental Health. I don’t mind if a Local Association has a view which is different. But they should be prepared to enter the debate, rather than only come in when they disagree...".

(Interview. Regional Director, Albion Region).

This view suggests a difference in perspective to that of the chairperson and secretary of Westhill MIND, who clearly felt that their Local Association was, and should be, autonomous (21)
This section will close with a case example of ways in which staff in Albion Region attempted to influence consumer involvement and other issues in a Local Association.

THE CASE OF SOUTHBURY ASSOCIATION FOR MENTAL HEALTH

Partly in an attempt to increase accountability, the Director of Albion Region suggested to two Local Associations, who were thought by regional staff not to be functioning well, that they undertook an objective setting exercise. One of these Associations, Southbury Association for Mental Health, was one of the oldest in the Region. It had been started by a former consultant psychiatrist and had an Executive Committee consisting mainly of mental health professionals, some of them retired, and little consumer involvement. The Regional Director said: "people in Southbury see the Local Association as reactionary and old-fashioned" (22).

Southbury Association had not attracted new membership, or initiated many new ideas or projects for several years. Its Executive Committee meetings, which were poorly attended, were held in the committee room of the local psychiatric hospital. A young and enthusiastic mental health social worker, who became the Association's secretary in the mid seventies, attempted to suggest changes, but received little support from other Executive Committee members, until a few new recruits joined in the early eighties. For many years, Albion MIND regional office had had little apparent contact with the Association, but in 1984 the Regional Director was invited to their Annual General Meeting, which at his suggestion, had a "where do we go from here?" theme. Soon after, he had a meeting with the Executive Committee, the purpose of which, according to the Secretary, was
"a nice way of saying: "You've got to shake things up"" (23). A few weeks later the Regional Director engaged the committee in an objective-setting exercise, and made it clear that changes were necessary if the Association was to remain affiliated to National MIND.

"..The Regional Director [wrote down various points], including "disaffiliate and remain the same", and "change: do what is suggested and remain affiliated..".

(Interview. Secretary of Southbury MIND).

The Regional Director also suggested to the Secretary: "if there is no other solution, we'll split from the old fogies" (i.e., set up a new Local Association).

After this meeting, a compromise was reached. The Executive Committee decided to remain affiliated. One of the newer members suggested retaining the main committee, which included three retired professionals, who would still have overall control, but meet less often; and to form subcommittees concerned with various activities.

The change in Southbury Association for Mental Health appears to have been achieved largely through one individual's persistence over many years, and the support that she received when new Executive Committee members were eventually recruited.
The Regional Director appeared to catalyze the change in three ways: firstly, through personal influence in an apparently good relationship with the Association's Secretary, who had, herself, wanted change for some time; secondly, through enabling the Executive Committee to examine various options; and thirdly, by making it clear that change was essential if the Local Association was to remain affiliated. The Regional Director's intervention was one of the most direct attempts noted during the period of fieldwork, by a Regional or National MIND staff member, to influence a Local Association.

Across England and Wales there was considerable variation in the extent and nature of Regional MIND staff's facilitation of consumer involvement in Local Associations. Two Regional Directors said that they did not think that this was particularly promoted or encouraged in their regions. One of these had only recently been established, and its Director felt that consumer involvement would spontaneously evolve in time (24).

Regional staff's attempts to influence local consumer involvement was probably greatest in "Region C". Previous reference has been made to ways in which staff in this Region had facilitated consumer involvement through staff advocacy and normalisation schemes in local statutory services, proposals for a Regional Consumer Council, and the holding of a meeting for consumers (25). According to respondents, there were five Local Associations in Region C with high consumer involvement; and in three which were studied, participants indicated that this was initiated by the local members themselves (26). Nevertheless, the Regional Development Officer indicated that some other Local Associations did not agree with certain of the views of herself or the Regional Director. "I tend to go in on my own
terms .. so I don't get invited very often", she said (27). The Regional Director commented:

"..we have circulated all Local Associations about the involvement of consumers.. I think many people [in Local Associations] genuinely don't understand.. If they did, they would be very shocked..

(Interview. Regional Director).

The Development Officer of another Region said that, when she first met individuals who were interested in setting up a Local Association, she often found that they were all mental health professionals. She then advised them to start a steering committee, consisting of about equal proportions of consumers, carers and professionals, advertised the new group locally, and sometimes visited statutory mental health services to invite users to participate in the committee.

"..I.. say.. "What's it like to be a receiver of services? Come and tell us..". Maybe I encourage social workers to encourage clients to come.. I have the first meeting as relaxed as possible. I might have it in a working Men's Club. The venue is important.. I do everything I can .. to help users of services come and say "It's bloody awful, mate"..

(Interview. Regional Development Officer).
This respondent stressed that she would reject an Executive Committee entirely consisting of consumers because it would not be "a representative group. I'm trying to get a cross-section of people". She emphasised the development of Local Associations as a means to achieve the personal growth of consumers, and the intrinsic value of consumer involvement to the individual, which she saw as more important than the benefit of such participation to the organisation. (28).

"..If it folds up after a year, this does not matter if people have grown.. [and developed] better awareness of mental illness, more responsibility, learning skills..".

(Interview. Regional Development Officer).

Another Regional Development Officer also stressed his emphasis on consumer involvement in his work with Local Associations.

"..I talk above the dangers of "volunteers" and "helped", instead of members who all have a lot to give, and consumers .. should be the ones who have the power.. In all my work, I aim to ensure consumers have most say, or as much as others.. I ask volunteers how they'd feel in the same position.. what I've said informs my attitude to my work and I try to persuade Local Associations to adopt that attitude..

(Interview. Regional Development Officer).
The Director of this Region felt that consumer involvement in Local Associations was facilitated "only... by encouraging them to recruit consumers or relatives..." (29). In contrast, the Development Officer cited plans for election from Local Associations onto the new Regional Council, and asking consumers to join Regional MIND in television broadcasts and in the Region's publications and exhibitions.

"...We say:" if you have mental health problems, this movement wants you". But having said that, we have a long way to go...".

(Interview. Regional Development Officer).

Finally, one Region employed a Development Officer, funded by statutory services, to set up Local Associations in an area which had never had a very active MIND presence. He described ways in which he had facilitated consumer involvement in new Local Associations. In one burgeoning Association:

"...I initiated and head-hunted for consumers in the steering committee, and later, consumers became quite articulate about their involvement and that of other consumers... I've increasingly defined consumer involvement as the top priority... if you keep at it, be a pain in the arse, professionals eventually see the importance of consumer involvement..."

(Interview. Regional Development Officer).
This respondent commented that another Association was "dominated by professionals" in the first six months of its existence. He felt that a consultant psychiatrist on the Executive Committee was "destructive and patronising to consumers. I wanted to get rid of him". The Development Officer did so by representing the consumer voice and being critical of psychiatry, and the psychiatrist eventually resigned. He also shared his antipsychiatry views with a dominant lay member of the Executive Committee, and emphasised to him the importance of consumer power, in order to influence his thinking. "Now he's saying what we need to do is change the composition of the Group... [that] consumers aren't powerful enough and the Local Association is professionally dominated". This respondent said that, since his influence on these Executive Committee members, professional influence had decreased, and a group of people with consumer experience had started a project (30).

Respondents in four of the Local Associations with high consumer involvement mentioned the influence of regional staff in facilitating this. (No participants in these Associations mentioned the influence of National MIND staff). In one region, one Association was started by two consumers who enlisted the help of the Regional Director and Regional Development Officer in setting it up; and another was initiated by the Regional Director, who encouraged a prominent local layperson to stand for election as an Executive Committee member, and to facilitate consumer involvement in a Local Association which lacked this (31).
THE INFLUENCE OF LOCAL ASSOCIATIONS ON NATIONAL MIND

National and Regional MIND respondents were asked how much influence Local Association participants had on National MIND policies (32). The majority felt that this was "slight", with several people saying "very little".

A few respondents felt that some Local Associations exerted influence through participants who were elected onto Council of Management. The National Director said there had been insufficient involvement of Local Associations in the past, but that at the time of fieldwork, "feedback moderates what we do" (33).

Some National MIND respondents referred to ways in which Local Associations influenced their own work or that of their Department (34). Several staff said that they responded to contacts from Local Associations or themselves initiated contact (35). One Assistant Director felt that the latter had influence "only when they point out new problems to us" (36).

Several respondents believed that there was more consumer involvement at local level, and one National MIND staff member suggested that, in order for consumer involvement to succeed in Headquarters, "National MIND needs to become a Local Association: a radical day centre run by consumers". (37). However, other respondents felt that certain attitudes in some Local Associations could hinder consumer involvement.

"...There would need to be a strong educative move to .. change Local Association attitudes.".

(Interview. National MIND staff member).
A high proportion of respondents said "don't know" or had no particular views on Forum, when asked to assess the influence of this body on National MIND (38). This suggests that Forum was not well known, or was not seen as particularly salient by many respondents. The small number who could answer this question assessed Forum's influence as being "nil" or "slight". A few respondents felt that it had provided useful opportunities to exchange opinions and information, and to put over the views of Local Association participants. Others said they had not found Forum of value.

A majority of the small number of Eastvale and Westhill MIND respondents who were asked about their Local Association's influence on National or Regional MIND rated this as "nil" (39). A few people felt that their Local Association's views were ignored:

"...views are thrown in the bin, and they write back and say what you should have said, or what they wanted you to say."

(Interview. Executive Committee Officer, Westhill MIND).

The Chairperson of Eastvale MIND said that she agreed with the proposed changes in structure and accountability in the organisation because she felt that Local Associations had insufficient influence on higher levels, although she had not encountered any particular problems in relation to this (40). In contrast, two officers of Westhill MIND commented on problems in communication and disagreements with National and Regional MIND (41), and the Secretary remarked that there should be "a direct link through a formal organisation with power... There is no opportunity for Local Associations to speak with one voice." (42).
Eastvale and Westhill MIND respondents were asked to assess the amount of influence of day centre or club members on National MIND policy. There was a large proportion of "don't Knows", especially from Eastvale day centre members. Of respondents who felt able to assess this, the majority said "Nil". However, most respondents felt club and day centre members should have such influence.

No day centre or club members in Eastvale or Westhill MIND participated in decision making at national or regional levels, and the same was true of only one out of nine respondents with consumer experience with positions of responsibility in Local Associations with high consumer involvement (43). Most of these participants did not desire involvement at other levels of the organisation. In contrast, a majority of Eastvale MIND day centre members said they would like such participation (44). However, most Eastvale and Westhill respondents, including active participants, had little knowledge of National or Regional MIND. In addition, some day centre members who desired participation at higher levels of the organisation, were unsure of ways in which they would like to be involved in National MIND policies. However, two actively involved Westhill MIND club members said they were keen to be members of the Consumer Advisory Network and to participate in the National MIND workshop on consumer involvement (45).

Overall, consumers who participated in Local Associations with high consumer involvement showed little interest in involvement in National or Regional MIND. Whilst these respondents talked enthusiastically about participation in their own Associations, several said "don't know" in reply
to questions about participation at other levels of the organisation. Several respondents made comments such as "no strong views" and "not made up my mind". Some had not heard of the Consumer Advisory Network, but a few individuals said they would like to be involved in it after an explanation by the interviewer.

In answer to specific questions, only one respondent expressed particular interest in being a member of both the Regional Council and Council of Management, two other respondents said that they would like to be on the latter, and a third said he would like membership of the Regional Council. Three respondents said they would like to be Forum members (46).

A few respondents in Local Associations with high consumer involvement mentioned lack of time and/or skills and experience as reasons for not wanting to participate in National and Regional MIND. One participant felt that the concerns of these levels of the organisation were not relevant to his Local Association. In contrast, three respondents expressed particular interest in involvement in National and Regional MIND (47). One respondent felt that he could contribute his intelligence and belief in human rights to National MIND, whilst another referred to the importance of consumer power:

"...I would like involvement very strongly... where I can have real effect on MIND and have plenty of authority dealing with matters I feel strongly about... Consumers who've suffered should have power in MIND...".

(Interview. Consumer member of Local Association with high consumer involvement).
Overall, nearly half of all respondents felt that the proposed changes in structure and accountability, if implemented, would lead to Local Associations' influence being "fair" or "considerable" than was the case with National MIND (48). Several respondents expressed uncertainty or scepticism about the likely influence of Local Associations. There was a number of comments about the likely effects on power in the organisation.

"..My views are cynical..I think unless MIND's top structure is democratised, all the rest will be whitewashed.. Although it's presented that Local Associations stand to gain on the National level, I think it'll be the reverse."

"..I think it's a good idea, but there's a general reluctance to devolve power away from the professional."

(Interviews. National MIND staff).

In contrast, another respondent felt that Local Associations would have increased power at both National and Regional levels, with influence on the running of the former and the appointment of staff.
Two respondents felt that the proposals would result in greater agreement between Local Associations and National MIND, and another that they would clarify the decision making process. Other respondents foresaw possible clashes between national and local participants, and an Assistant Director feared that Local Associations might restrict campaigning (49).

**LOCAL INFLUENCE ON CONSUMER INVOLVEMENT IN NATIONAL/REGIONAL MIND**

One weakness of the study is that respondents were asked little about the influence of Local Association participants on Regional and National MIND policies for consumer involvement (50). However, a number of individuals, particularly in regional offices, commented on this.

The Local Associations Co-ordinator said that Local Associations did not normally try to influence consumer involvement in National MIND. Several respondents at National and Regional levels felt that it could best be achieved through a "bottom up" approach; and that establishing consumer involvement at local level would facilitate such participation in Regions and Headquarters.

"...if consumers are more involved in Local Association Executive Committees, this is more likely to move up the system."

"...I would like to see more emphasis on consumer involvement at local level, and build up from there."

(Interviews. National MIND respondents).
"...If we increase consumer involvement at local level, this will lead to an increase of consumer involvement in Regional Council and Council of Management...".

(Interview. Regional Development Officer).

One Westhill MIND staff member said she had been in touch with some Regional and National MIND staff concerning plans to increase consumer involvement within the Local Association and in local statutory services, and about developments in consumer involvement in National MIND (51). Apart from this, there appeared to be no attempts by Eastvale and Westhill MIND participants to contact Regional or National MIND about consumer involvement, or to influence such participation at these levels. One respondent said that members of her Local Association with high consumer involvement had written to National MIND about this issue because they felt that "the philosophy of the consumer should be pushed much more" (52).

Regional respondents' views varied on the extent that Local Associations influenced regional policies (53). Two individuals felt that local participants had little influence, two said that this varied according to the Local Association, whilst one respondent felt that it was:

"...quite a bit because staff identify issues of concern to Local Associations, and try to produce information sheets and workshops to provide this. I know it's true in most other Regions as well: they keep an ear out on what is happening [and try to respond]..."

(Interview. Regional Director).
One Regional Development Officer said that although Local Associations had opportunities to influence the Region in relation to consumer involvement, they did not bother to take this up. In two other Regions, the influence of Local Associations depended, at least, in part, on how far regional staff agreed with their views. "We listen if they have sensible things to say", said one Regional Development Officer, "and seek out their opinion." (54).

Another respondent indicated that local influence depended on the extent to which Associations communicated with regional staff, and their degree of consumer involvement. If the latter was high, they were more likely to have influence.

"...the closer we work with a local Group, the more reciprocity exists. What Midford MIND and Northbridge MIND [Local Associations with high consumer involvement] say, we tend to respond to, but some like Eastborough MIND [a Local Association run on traditional lines] we hardly say anything to each other. We'd be very resistant to taking on line the suggestions they make to us. they have no influence upon this office."

(Interview. Regional Development Officer).

Another Regional Development Officer commented:

"...I think Local Associations would say [their influence on Regional MIND] was "Nil"... we do not see them as seeing consumer involvement as important."

Interview. Regional Development Officer).
Most respondents felt that the changes in structure and accountability would result in a slight or fair increase in consumer involvement, or were unable to estimate this (Table 14.3).

**TABLE 14.3**

RESPONDENTS' VIEWS ON THE LIKELY INCREASE IN CONSUMER INVOLVEMENT RESULTING FROM THE CHANGES IN STRUCTURE AND ACCOUNTABILITY.

<table>
<thead>
<tr>
<th>Perception</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerable/Marked</td>
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</tr>
<tr>
<td>Fair</td>
<td>7</td>
</tr>
<tr>
<td>Slight</td>
<td>6</td>
</tr>
<tr>
<td>Nil</td>
<td>4</td>
</tr>
<tr>
<td>Don't Know</td>
<td>7</td>
</tr>
<tr>
<td>Other Response</td>
<td>4</td>
</tr>
</tbody>
</table>

Three respondents specifically mentioned Council of Management or Regional Councils as providing a means to increase consumer involvement.
"...Consumers will have more say through the management structure...".

(Interview. National MIND staff member).

"...Through Regional Councils, I think there is a link which could be exploited in terms of consumer involvement. It could be a positive move if there's the will to do it...".

(Interview. Westhill MIND staff member).

Other respondents expressed doubts. "It leaves the door wide open to consumer involvement, but I can't see it spelled out anywhere", said a Council of Management member (55), whilst a regional respondent felt that increased consumer involvement throughout the organisation depended on "the extent that we are able to encourage consumer involvement in local groups" (56). Other participants felt that an increase of influence of Local Associations on National MIND was unlikely. Two respondents said this was because consumers involved in Local Associations were not likely to be elected onto Regional Councils and Council of Management (57). A member of the latter commented:

"...If the message gets through to Local Associations of increased involvement, it will increase. If it doesn't get through...it won't. Consumer involvement is not inherent in the system..."

(Interview. Council of Management member).
Two staff members questioned whether the changes in structure and accountability would alter power-relations in the organisation.

"...I think influence is not possible without a certain amount of power, and as I see it, the power structure is not changing...".

(Interview. National MIND staff member).

"...Will Regional Councils have any more influence on us [regional staff]?... people [in the organisation] do not talk about power in any sense...".

(Interview. Regional Development Officer).

Almost all MIND respondents were enthusiastic about increased consumer involvement, but one staff member felt that attempts to increase the influence of Local Association participants and consumers might serve only to "make us feel comfortable with our intentions" (58). A mental health professional on the Council of Management feared that such involvement would be "radical" with "a lot of conflict" between the Consumer Advisory Network on the one hand, and Council of Management and Local Associations on the other (59). However, this view of potential conflict was expressed by very few other respondents.
This Chapter has included an examination of the influence of National/Regional MIND on Local Associations, and vice versa, particularly in relation to consumer involvement. Most National MIND respondents felt that influence of Headquarters on Local Associations was slight, or that it varied, depending on the Association. Problems related to communication and Local Associations' autonomy were said to limit the influence of National and Regional MIND, but a number of staff at Headquarters described ways in which they had tried to influence consumer involvement at local level. Few respondents thought that the proposed changes in structure and accountability would result in more than a slight increase in National's MIND's influence on Local Associations.

In Chapter 13 it was concluded that National/Regional MIND had few resources with which to influence Local Associations, other than personal influence. Several Regional MIND staff described ways in which they used their personal influence to increase consumer involvement locally. This included various strategies, such as enabling participants to think in particular ways about the needs of consumers, stating the importance of consumer involvement, and giving more credence to the views of members of Associations where such participation was high. A few respondents described ways of influencing consumer involvement which were intended to be covert: i.e. not immediately obvious to participants. ("I try to get people to do what I want them to, without their realising it", said one Regional Development Officer).
Only one National MIND respondent felt that Local Associations' influence on Headquarters was more than slight, although some National MIND staff described ways in which local participants influenced their work. The majority of Eastvale and Westhill MIND respondents said that day centre and club members had no influence on Headquarters, or replied "don't know". Most respondents in Local Associations with high consumer involvement did not want to participate in other levels of the organisation. A majority of Eastvale MIND day centre members said they would like to be involved, but some were unsure of ways in which they could do so. There were apparently few attempts by local participants to influence consumer involvement in National/Regional MIND. Several National MIND respondents felt that an increase in consumer involvement would lead to similar increases in other levels of the organisation.

Finally, less than half of respondents said that the proposed changes in structure and accountability would result in more than slight influence of Local Associations on National MIND. About two-thirds of respondents who felt able to give an opinion believed that the proposed changes would result in a fair or slight increase in consumer involvement.
CHAPTER 15

SUMMARY AND DISCUSSION

This Chapter includes a summary and discussion of the main findings of the study, in relations to values, the complex nature of participation, its benefits and problems, and factors which facilitated and hindered consumer involvement.

THE VALUE ATTACHED TO PARTICIPATION

There is evidence from the literature that, since the late fifties, consumer participation has been seen as beneficial by many politicians, policy makers and professionals, - and by some users of services, themselves. This was particularly true during the sixties and early seventies in both the UK and the USA (1).

In this country, there has been a recent revival of interest in certain aspects of participation, with an increase of consumer organisations, characterised by solidarity, which challenge traditional mental health services (2). Since the period of fieldwork (late 1984 to 1985), consumer involvement in MIND has, in some ways, at least, progressed and increased. The Consumer Advisory Network has been effectively functioning for about six years. The proposed changes in structure and
accountability were implemented, and people who have made their consumer experience explicit have been elected as officers and members onto the Council of Management (3). One of the Local Associations which was studied in depth ("Westhill MIND") elected consumers onto its Executive Committee soon after most of the research was completed in this Local Association, and facilitated patient participation in local psychiatric hospitals (4). Recently, there has been an increased interest, amongst both consumers and professionals, in various forms of advocacy in mental health services (5), including the setting up of Patients Councils (6). The Department of Health report on Ashworth Special Hospital recommended the setting up of a patients' advocacy service (7), similar to that established at other psychiatric hospitals (8).

In addition, there has recently been a considerable increase of interest in certain aspects of the rights of users of public services, and in consumerism. Proponents of the latter have stated that this is a move towards providing services of a higher quality, with greater choice, power and rights to the service user, and greater interest in their views (9). Some authorities have argued that the term "consumer" is, itself, empowering, and that words such as "recipient" or "patient" place the user of a service in a passive or dependent role (10). However, some critics state that the term "consumer" is stigmatising, or that it is inappropriate to apply a term from market economics to public health and social services, where there is little choice, autonomy or power (11). Furthermore, some recipients of such services receive them against their
will, or because they have little choice (12), and this particularly applies to users of mental health facilities, whose perspectives of the appropriateness of services may considerably differ from those of providers (13).

Some of the divergent views about the nature of consumer participation relate to values and conceptual issues. Several critics have commented that participation is seen as a "value word": seen by many people as being beneficial, with little consideration of its meaning or components, or how it can best be achieved (14).

My research has helped me to reflect on my own values, and those of other proponents of participation. Although some authorities have emphasised the importance of a social science which is "objective" and "value free" (15), many have stressed that complete value neutrality is impossible, and that social scientists need to make their values explicit, and ensure that these impinge as little as possible on methodology and data analysis (16).

The work for this thesis has involved both personal and academic discovery. As the study progressed, I became increasingly aware of my own values. Criticisms in the literature of many proponents' uncritical enthusiasm for consumer participation enabled me to reflect on my own desire to increase this in my work as a psychiatric nurse, and my choice of topic for research. My values also influenced the choice of questions for pilot interviews in the preliminary fieldwork, in which respondents
were asked to rate the extent to which various components of consumer involvement existed in their Local Associations (17). These "components" were based largely on my assumptions about the nature of consumer involvement, although the rating scale was useful as an initial exploration of the concept.

More open-ended questions helped me to reflect on respondents' own views, rather than impose my own assumptions and "measurements". As fieldwork progressed, I became more interested in respondents' perceptions and understandings. This interest in their versions of reality resembled a phenomenological approach (18), although I did not consciously decide to use this. I became more aware of my tendency to uncritically see consumer involvement as always beneficial: to regard organisations which worked to achieve this as "good", and those which did not as "bad". It is difficult to assess the extent that these values influenced this study, (19), but as the field research and literature review progressed, I became more aware of the complex nature of consumer involvement, and increasingly interested in what respondents had to say about it. I attempted to devise questions which would critically examine its nature, and its benefits and problems.

THE COMPLEX NATURE OF CONSUMER INVOLVEMENT

Several authorities have commented on the lack of clear definition or conceptualisation of the term "participation", which has been given a wide range of meanings in the literature (20). No definitions of consumer participation were found in the literature surveyed, and the following definition was proposed in Chapter 3:
The involvement of users of services in responsibility and/or decision making which has an intended impact on services and/or policies which affect the individual participant and/or other service users.

A literature search failed to find any differences between "consumer participation" and "consumer involvement", and the two terms have been used interchangeably in this thesis. Although the former term is used more frequently in the literature, consumer involvement was used by MIND respondents. However, many respondents were unclear about its meaning, or that of "consumer", and there was a wide range of views about the meanings of these terms (21).

Data from the literature review and field research suggests that it is difficult to effectively implement policies or goals for consumer involvement without being aware of the complex nature of the phenomenon. Many professionals and policy makers have uncritically assumed that consumer involvement is a "good thing", without examining the nature, types, levels and degrees and limitations of participation, and who is to participate (22). Data from the research suggests that policies for consumer involvement can be more effectively implemented if attempts are made to consider a number of questions. These include:

* For this particular group of consumers, what is the optimum type, level and degree of participation? Who decides this?
* What are the limitations of consumer involvement? Who decides this?

* What are the aims or goals of consumer involvement? How can they best be achieved?

* What are the perceived benefits and problems of consumer involvement: to the participating individual and to the organisation?

* What factors facilitate or hinder consumer involvement? How can "hindering" factors be overcome?

* Who is to be involved in the planning and facilitation of consumer involvement?

The rest of this Chapter and the final Chapter will evaluate the findings of the study in relation to these questions.

In Chapter 3 it was proposed that the nature and characteristics of participation could best be understood by examining various dimensions. These include:

1. Degrees.

2. Levels.
3. Components, types and methods.

4. Modes of intervention.

5. Types of participant.

Data from the fieldwork of the present study suggests that there are three other components which need to be considered in attempts to understand the nature of participation or to implement policies to achieve or increase it. These include the extent to which participation is:

6. Covert or overt. ("Openness").

7. Conscious or unconscious. ("Consciousness").

8. Formal or informal. ("Formality").

Each of these will be considered in turn.

DIMENSIONS OF CONSUMER INVOLVEMENT

Degrees of participation refer to varying amounts of involvement from "no participation" to "total control of the organisation", and a number of typologies was considered. A typology of degrees of consumer involvement
was produced, based on that of Brager et al (23), including "nil", "explanation", "consultation", "direct representation", "equal participation" and "total running of the organisation".

Surprisingly, the literature reviewed did not include any typologies of levels of participation, so one was presented in Chapter 3. Levels of consumer involvement vary from individual (e.g. within a professional - client relationship); participation in a group, small organisation or minor committee; involvement in the running of large institutions or in a major committee; and in attempted or actual influence at local government, regional, and central government levels (24).

Figure 15.1 (page 481) represents levels and degrees of consumer involvement. For each level, it is possible to have varying degrees of participation. Thus, involvement in Central Government could range from nil or receiving information from a Department to serving as a consumer representative on a committee or on an advisory committee consisting entirely of consumers.

DEGREES AND LEVELS OF CONSUMER INVOLVEMENT IN MIND

During the period of fieldwork, there was no consumer involvement in National MIND at degrees four and five (equal participation and total running of the organisation). At least one member of Council of Management had had consumer experience, according to one staff member,
Figure 15.1
Square of Degrees and Levels of Consumer Involvement
and, in a sense, such involvement was at degree three (direct representation). However, any members of Council of Management with consumer experience did not make explicit that they were there to represent the views of consumers (25). In contrast, in 1991, some individuals with consumer experience made it clear in manifestos that this was why they were standing for election to Council (26).

Volunteers with consumer experience contributed to the running of National MIND, but were not involved in decision making processes. There was a limited amount of consumer representation in National MIND departments, including the employment of a few staff who said that they had had consumer experience. The Legal Department directly involved consumer representatives in certain "test cases" (27), whilst the Training and Education Department facilitated consumer involvement in the teaching of professionals and in presentation of papers and running of sessions at the 1985 Annual Conference. Consumers were also actively involved in a workshop on consumer involvement for Local Associations. The Consumer Advisory Network was planned to facilitate direct representation, and the proposed changes in structure and accountability were intended to enable both involvement at this level, and something approaching equal participation in Regional Councils and Council of Management. Few respondents felt that MIND should be run entirely by consumers (28).

In most departments there was consumer involvement at degrees one and two, with considerable advice and information given, some of which was
about the organisation. Consultation (degree two) was limited although many staff said they informally took consumers' views into account when making decisions. In MIND regions, staff in one office had started meetings with consumers to ascertain their views (degree three) and informal consultation between consumers and development officers occurred in all the established regions (29).

Within Local Associations degrees of consumer involvement varied considerably. A few, such as Southbury Association for Mental Health (described in Chapter 14) had little or none at a certain stage of their existence. Westhill MIND's Executive Committee occasionally provided explanations to consumers or consulted with them (degrees one and two), but many club members, and some Executive Committee participants felt that this was insufficient, and that, in addition, consumers should be directly represented or have equal participation. (These degrees of consumer involvement were achieved, in some aspects of the Association's work, soon after the period of fieldwork and the committee for patient participation was completely run by consumers, although initiated by a Westhill MIND staff member). There was somewhat more than equal participation in the running of the social clubs, with consumers making most of the major decisions (30). In Eastvale MIND there was a fair amount of consultation, and considerable direct representation from the Association's inception. There was equal participation in some aspects of the running of the day centre, (although responsibility rested with its manager), but not in the running of the Association, as its officers had always been "non consumers". Several of the Local Associations with
high consumer involvement had equal participation, but none had participation at degree 5 (total running of the organisation) (31). Indeed, most respondents felt that MIND should not be completely consumer-run, and this appeared to be related to the diverse, complex aims and varied membership of the organisation (32). However, Campaign Against Psychiatric Oppression was found to be almost consumer run (with just one professional member), and Depressives Anonymous was entirely run by people who had experienced depression (33).

Within Local Associations there was considerable consumer involvement at levels 1 and 2, with many instances of individuals making their own decisions about how they used Associations' facilities and there was much participation in the running of the latter, and in giving help and support to others. This was certainly the case in relation to Eastvale MIND's day centre and Westhill MIND's social clubs, and in the Local Associations with high consumer involvement (34). There was a small amount of Level 3 participation, in that some consumers served on Executive Committees of Local Associations which were large in terms of the number of services they provided and the amount of funding which they received. A few consumers were involved in attempts to influence local services (Level 4), such as the chairperson of an Association who was also a member of a Community Health Council. Some club members in Westhill MIND were keen to be involved in local campaigning, and a sub-group for this activity was started soon after the period of fieldwork. No examples of Levels 5 or 6 (attempts to influence regional authorities or Central Government) were found in Local Associations; but
consumers in the Matthew Trust and Campaign Against Psychiatric Oppression, and relatives in the National Schizophrenia Fellowship had all been actively involved in influencing Central Government through lobbying and other means (35).

Within National MIND, volunteers participated at lower levels: e.g. deciding when they would come to Headquarters, and how much work they would do. Some volunteers contributed considerably to the work of particular departments, although this did not extend to decision making. However, there was little consumer involvement in the running of National MIND (as far as could be assessed, given that there was a certain amount of covert consumer involvement) (36).

Participants at Headquarters made considerable efforts to influence central government, and in some instances, local services. Interviews with civil servants and a few politicians suggested that National MIND was by far the most influential voluntary organisation for mental health, in relation to influencing central government policy. Respondents indicated that the (then) D.H.S.S. generally viewed MIND as a credible organisation, and an important member of the "policy community" on mental health services (37). Consumers were rarely directly involved in attempts to make representations to central government, although there was some indirect consumer participation, in that the Legal Department, in particular, sometimes took up the cases of particular individuals when campaigning for change (38). At regional level, staff attempted to influence Health and Social Services, (particularly in "Region C"), where staff had introduced principles of normalisation into statutory services for people with mental health problems (39).
COMPONENTS, TYPES AND METHODS OF PARTICIPATION.

The complexity of participation is also reflected in its many components, and wide variety of types and methods. Components described in the literature include sharing activities with others, a subjective feeling of being involved, self help, the exercising of choice and rights, and power (40). Types and methods to achieve participation appear to overlap (41). They include self-help groups, self-advocacy, the raising of consciousness and establishing a shared identity and certain types of professional - client relationship. Participation can also be facilitated through the provision of information and meetings to consult consumers, representation on committees, consumer satisfaction studies, personal accounts by consumers, and responsibility in a variety of services and in campaigning (42).

Several authors have commented that power is a crucial component of participation, and that the latter cannot be increased unless there is a redistribution of power (43). It is suggested that such a view is problematic because:

1. It ignores the complex nature of participation. Some degrees of participation, such as providing information and consultation do not necessarily involve major shifts in power.

2. Many MIND consumers stated that they were happy to have opportunities to put forward views or take on responsibility, but that they did not want positions of power: e.g. in running their Local Association or National MIND (44).
Consumer involvement has been described in the provision and running of a variety of services (including some which have been entirely consumer-run) and in campaigning and lobbying (45).

Within MIND, there was considerable consumer involvement at local level in the provision of mutual support, and in making contributions to, or running services such as social clubs and day centres. Indeed, Eastvale MIND's day centre could not have been run without consumer involvement. There was some participation of consumers in fund raising, and several Local Associations, including Eastvale MIND, were found to have consumer involvement at Executive Committee level. Consumers occupied officer positions in most of the Local Associations with high consumer involvement. At least three of the latter were founded by people who had been users of mental health services (46).

MODE OF INTERVENTION

Another dimension of consumer involvement is the mode of intervention, a term used by Brager et al to describe the relationship between consumers and decision makers. These authors describe "collaboration", "campaigning", and "contest or disruption". The present study found that there was a clash of perspectives between participants in some Local
Associations and those at Headquarters. Many of the former co-operated with local authorities and received funding from them, and disagreed with National MIND campaigning (48). Although at times, the National Schizophrenia Fellowship and Manic Depression Fellowship criticised examples of bad professional practice, in general, members subscribed to medical models of mental illness, were keen to work with professionals, and involved them in the organisation. In contrast, members of Campaign Against Psychiatric Oppression expressed a commitment to overthrowing the mental health system (49).

Chamberlin distinguishes between partnership and separatist models of participation in mental health services which are run entirely by consumers. In the former, consumers invite professionals to work with them, whilst in separatist organisations, professionals are refused membership or co-option (50). There was a partnership approach in all the voluntary organisations studied, including Campaign Against Psychiatric Oppression. Whilst many consumers, in MIND and elsewhere, were critical of professionals, the majority were apparently happy to work with those whom they perceived to be sympathetic. Recent more radical British consumer movements for mental health have also adopted a partnership approach, which contrasts with the separatist patients' rights movements of North America (51).
Another dimension of consumer involvement concerns the type of participants who should be involved in decision making. Some authors have argued that "consumers" include taxpayers, carers and relatives of service users, and the entire population, as potential users of particular services (52). Several MIND respondents included people in the last two groups in their definition of the term (53).

Data from the research on MIND suggests that there are three other components of consumer involvement which appear to be little mentioned in the literature. These relate to consumer involvement being: covert or overt; conscious or unconscious; formal or informal.

COVERT AND OVERT INVOLVEMENT

It was difficult to assess the exact amount of consumer involvement in National MIND because it was not clear to participants which individuals were involved because of their consumer experience; and respondents were not directly asked this, as it was felt to be a personal matter. Several respondents said that, whilst some National MIND participants had had consumer experience, they did not normally make it clear that they were involved for this reason. Indeed, a few respondents said that some individuals were involved in the organisation not because of their consumer experience, but because they felt they had something to
contribute to the organisation from other experiences and skills (54). For example, the Treasurer of one Local Association said that he was involved because of his wish to apply his expertise as an accountant, and not because he had been a user of mental health services (55).

A small number of staff members at Headquarters felt strongly that National MIND participants should "come out", and make their consumer experience explicit. This was felt to be of value to other consumers, and to make it clear to the public that anyone could experience mental health problems (56). By the early nineties, several candidates standing for election to the Council of Management, and the many members of the Consumer Advisory Network (which had a membership of 450 in 1989) had made their consumer experience explicit (57).

CONSCIOUS AND UNCONSCIOUS INVOLVEMENT

Data from the study indicated that consumers who were involved, and other participants who encouraged this, could be divided into two groups. There were those who expressed a conscious, and often well articulated desire to increase consumer involvement. These individuals, including many in Local Associations with high consumer involvement, were often keen to raise the self esteem and consciousness of consumers and emphasise the contribution which they could make. They were sometimes critical of mental health professionals and services (58).
The second group included people involved in Local Associations whose high consumer involvement did not appear to stem from a conscious desire to involve consumers. Amongst these participants, consumer involvement seemed to be a "taken for granted" aspect of the reality of the Local Association. In some cases, consumer involvement was seen as, not so much valuable in itself, but for the end result which is produced i.e. it helped with fund raising or the provision of a service (59).

Eastvale MIND is an interesting example of a Local Association where such involvement was partly conscious, partly unconscious. Thus, the social workers who founded the Association consciously facilitated consumer involvement from the start because they felt that such participation would benefit consumers. During fieldwork some participants provided opportunities for consumer involvement: e.g. through the open meetings in the day centre, and (in the case of professionals) by deciding to become co-opted, rather than full members of the Executive Committee, and determining not to dominate the proceedings of meetings. On the other hand, much consumer involvement was unconscious. For example, one day centre member started a self help group for people, who, like herself, had depression, because she perceived the need for this, rather than because she wanted to participate. Some day centre members who took on the role of stewards stressed the extrinsic rewards of their involvement, rather than the benefits of taking on responsibility; and this activity was not described as "consumer involvement". A few respondents indicated that day centre members had taken on some responsibilities, not entirely because participants perceived consumer involvement as of value in itself, but to obviate a shortage of "non consumer" volunteers (60).
In Chapter 7 a description was given of two very different forms of consumer involvement. In Westhill MIND social clubs consumer involvement was informal, unplanned and spontaneous. In one social club, in particular, it was difficult to differentiate between "members" and "volunteers" and some respondents saw themselves as occupying both roles, or felt that it was meaningless to distinguish between the two. Participants were keen to avoid making invidious distinctions between participants, or to formalise particular responsibilities. Anyone could decide to perform particular tasks or make decisions, and this was often done in an ad hoc way. Attempts by a former participant to impose structure had been firmly rejected (61).

In Eastvale MIND day centre some consumer involvement was informal, but much of it was formal and characterised by high "role visibility": i.e. it was often very clear to a newcomer that a particular day centre member (called a "steward") was in charge. Stewards had particular responsibilities and tasks which were clearly defined, and were responsible for the day centre in the absence of staff. They had a duty rota placed in a prominent position, were the only day centre members allowed access to the kitchen, and were expected to follow certain rules, set and clearly spelt out by the Association's officers or the centre manager, to whom they were accountable (62).
It is suggested that the extent to which consumer involvement is overt, conscious and formal comprise additional components of participation which add to its complexity, and which need to be considered by participants in voluntary and statutory organisations who are facilitating consumer involvement (63).

Figure 15.2 illustrates the dimensions of participation which, it is suggested, need to be considered in attempts to understand the nature of the concept, and to effectively implement policies to increase consumer involvement.

THE BENEFITS AND PROBLEMS OF CONSUMER INVOLVEMENT

The rest of the chapter examines and summarises the main findings concerning the benefits and problems of consumer involvement, and factors which facilitated and hindered such participation.

The extent to which consumer involvement was seen as beneficial depended, in part, on its salience to participants. Within MIND this was indicated by stated commitments in Annual Reports to increase such participation, policy initiatives, and the general agreement, expressed by almost all respondents, that consumer involvement in MIND should be increased, with some individuals expressing particular enthusiasm. However, Local Association consumers who were actively involved did not usually want to
Figure 15.2
Octagon of Consumer Involvement:
Eight-Dimensional Model Illustrating Various Dimensions of Participation

- **Consciousness**: Conscious or Unconscious
- **Formality**: Formal or Informal
- **Openness**: Overt or Covert
- **Mode of Intervention**: Cooperation or Opposition
- **Types of Participant**: Consumers/Survivors - Allies, Separatism or Partnership
- **Components**: Service Provision or Advocacy/Campaigning
- **Degrees**: From NIL / Individual to Total Responsibility
- **Levels**: From NIL / Individual decisions to Central Government
participate at other levels of the organisation, and several respondents commented that many consumers lacked the motivation to participate. In addition, consumer involvement was not often mentioned by consumers in general as a main aim of the organisation, a reason for joining a Local Association, or something which they particularly liked or disliked. Data from interviews indicated that this was partly because consumer involvement was seen as being intrinsic to various aspects of MIND's work, rather than a separate aim in itself. In addition, some individuals participated without being aware that this constituted "consumer involvement". For these participants, their own involvement, or that of other consumers was unremarked, unconceptualised, a "taken for granted" part of events in their Local Association (64).

The most frequently reported benefits of consumer involvement to consumers, themselves, were psychological gains, feeling valued and of use, and particular gains from the experience of being involved in responsibility and decision making, and from giving and receiving help. The most frequently reported problems related to consumers having difficulty in taking on responsibility, their differences in perspective from other participants and organisational factors (65).

Some respondents, especially National MIND volunteers and Eastvale MIND day centre members, mentioned extrinsic benefits from their involvement, including the availability of interesting activities, free or cheap drinks and food, security and "somewhere to go".
Psychological benefits of participation are described in the literature, particularly in relation to industry and personal social services. Several MIND respondents referred to increases in confidence and self-esteem, although a smaller number described factors within the individual or the organisation which made this difficult. Feeling valued and of use, as a result of consumer involvement, was also described, especially in Eastvale MIND, where some members indicated that participation in the day centre was better than their previous lonely and isolated lives.

Although National MIND volunteers generally reported satisfaction with the work in which they were involved, some staff members felt that, on occasions, insufficient attention was given to their welfare, and that they were given unrewarding and demeaning tasks. A few respondents felt that consumer involvement helped particular individuals to gain new skills and knowledge; and five volunteers said that their work in National MIND had helped them to develop skills which could be used in paid employment.

Whilst some respondents felt that consumers benefited from taking on responsibility, others felt that this was stressful to people with limited self-esteem, confidence or motivation. Lack of confidence was said to make it particularly hard for some consumers to cope with meetings.
Several respondents, mostly at local level, felt that consumers were empowered from their participation, and a few people in Local Associations with high consumer involvement particularly emphasised this. However, some National MIND staff members felt that the nature of volunteers' work disempowered them, and failed to raise their status or give them real responsibility.

BENEFITS AND PROBLEMS TO THE ORGANISATION

Rather more problems than benefits of consumer involvement to the organisation were described. The most frequently reported benefit, and the most frequently reported problem in relation to this, were consumer views and perspectives. Other frequently reported benefits included the provision of help and support to other consumers, and the skills and abilities which particular individuals contributed. Frequently mentioned problems to the organisation included difficulties which arose because of particular individuals' personality traits or mental health problems, and difficulty in taking on responsibility and decision making (66).

Many consumers mentioned the benefits of giving and receiving mutual support, and the friendships which they developed in Local Associations or in the National office. Several people described ways in which their own experience of mental health problems enabled them to give to others in distress; and a few people said that their efforts to help others had made them feel empowered.
Some of the Local Associations owed their founding or continued existence to the efforts and skills of consumers, and there was evidence that it would have been difficult to have run many Local Associations without consumer input. Several respondents described particular skills, and abilities which individual consumers contributed to Local Associations or to Headquarters, and a number of Westhill MIND respondents felt that increases in consumer involvement would benefit the Association in various ways.

However, there were about as many comments on consumers' difficulties in taking on responsibility and participation in decision making, including involvement in meetings. This was often attributed to lack of confidence or motivation, which were frequently said to be caused by mental health problems.

A number of authorities have referred to clashes of consumer views, interests and perspectives with those of professionals and others in authority. Slightly more benefits than problems of the consumer perspective were described by MIND respondents.

Several people mentioned the value of consumer views, especially in ensuring that services provided reflected consumers' expressed needs and interests. However, several respondents felt that consumers' views were insufficiently considered, particularly in Westhill MIND respondents.

Problems with the consumer perspective, such as bias, subjectivity and narrowness were often referred to, but some respondents argued that differences and disagreements could be healthy or creative.
The problem of representativeness has been described by many authors: the extent to which people who serve on committees, or otherwise participate, are representative of other consumers. It has been found that many consumer representatives are white, male, middle class and middle aged (67). A number of respondents referred to the problems of ensuring that MIND represented the views of the majority of consumers, not just those who were active participants. The problem of adequately representing consumers with divergent or conflicting views was also occasionally raised. A few people felt that the language used in MIND literature and meetings did not enable the participation of some consumers, but efforts were made to make the 1985 Annual Conference relevant and accessible to service users. In addition, steps were taken to ensure better accessibility and representation of consumers who were members of black and minority ethnic groups and women (68).

**FACTORS WHICH FACILITATED AND HINDERED CONSUMER INVOLVEMENT**

An examination was made of factors which facilitated or hindered consumer involvement in MIND. Those most frequently mentioned included the role of consumer and professional volunteers and of staff, and organisational factors such as opportunities for consumer involvement and related policies (69).
Examples of consumer involvement which were initiated by consumers themselves have been described in a variety of services, including mental health. There has been an extensive patients rights movement in North America since the early seventies, and a large increase in consumer movements for mental health in the U.K. and other European countries since the mid eighties (70).

Consumers and/or their relatives founded and ran all the other voluntary organisations which were studied and consumers had been founding members in five local MIND Associations (71). Data from interviews indicated that the existence or revival of four Associations was due solely to the efforts of consumers. The latter were actively involved in three other Associations which had been heavily dominated by professionals. Two respondents described their facilitation of the participation of other consumers. Instances were found of projects which would have been impossible to run without consumer involvement, most notably Eastvale MIND’s day centre which was open every day of the year.

Consumers’ skills, qualities and abilities, or their lack, have been found to affect their participation in a variety of services. Several respondents mentioned the considerable contributions and skills of many consumers, both in MIND and in the other voluntary organisations studied. However, MIND respondents, particularly in Eastvale and Westhill, more frequently referred to the lack of consumers’ skills as hindering consumer involvement. Lack of confidence was often described
and this was variously attributed to negative self-image, mental health problems, lack of communication and other skills, and the formal structure of meetings. Some respondents felt that consumers' confidence could be increased through training (e.g. in getting used to meetings), or stated that consumers should serve on committees only if their mental health problems did not affect their ability to function. However a smaller number said that organisational or committee structures should be changed, or additional meetings provided, to accommodate consumers' needs and aptitudes (72).

PARTICIPANTS' ATTITUDES

The negative self-images of people who have been subject to discrimination, including individuals with mental health problems, has been described. A raising of consciousness, and solidarity, with a sharing of experience of oppression ("coming out") is said to be essential to facilitate participation, and to combat negative attitudes (73). There were mixed views about whether National MIND participants should "come out" and declare their consumer experience. Some respondents considered that it was stigmatising to make such a differentiation, whilst others felt that this would make the organisation more accessible to consumers (74).

According to Chamberlin, consumers, as well as professionals and laypeople, can experience mentalism: prejudiced attitudes towards people with mental health problems (75). Some respondents felt that the
attitudes and personalities of certain participants hindered consumer involvement. Thus, some consumers were seen as being domineering, controlling or argumentative. However, other participants described facilitative attitudes: e.g. the wish to empower consumers and enable them to participate. These respondents included a number of consumers who wished to use their own experience to help others in similar situations (76).

Interview responses suggested that lay and professional participants' beliefs about consumers' ability to participate might have influenced consumer involvement. It is difficult to disentangle the extent to which a mental health problem actually made it difficult for consumers to participate; and participants' beliefs about its effects (77) "That which we assume to be real is real in its consequences" (78). Some studies suggest that mental health professionals have sometimes wrongly assumed that all areas of behaviour and the ability to make decisions are affected by mental disorder, when this may not be the case (79). The data suggests that such beliefs, are inimical to consumer involvement and this will be further considered in the next chapter (80).

Some respondents felt that consumers were not often able to manage responsibility, and this was particularly stressed by members of a local branch of the National Schizophrenia Fellowship, which was run mainly by relatives. Others felt that consumers were only unable to take on
responsibility during times of acute mental health problems, and a few respondents described strategies developed by members to cope with times when this occurred. Thus, a member of the Manic Depression Fellowship, who emphasised the important contribution which consumers made to the organisation, described a system of "shadow" officers, who could step in and take over the role of the main officer if (s)he became acutely ill (81).

THE ROLE OF PROFESSIONALS

The literature contains many examples of professionals' initiatives to increase consumer involvement, including a growth in interest in consumer views and improvements in individualised care. However, professionals have been criticised for ignoring consumer perspectives, exerting undue power, and for holding paternalistic and stigmatising attitudes (82).

Many MIND respondents stated that professionals' attitudes had a particularly crucial effect on consumer involvement, and examples which militated against this were mentioned far more frequently than facilitating factors. The desire of professionals to enable consumer involvement, as occurred in the setting up of Eastvale MIND, appeared to be particularly important. Other perceived facilitating factors included professionals' desire to learn from consumers, an interest in their perspectives, and a conscious effort not to dominate decision making. Factors said to hinder consumer involvement included an excessive number of professionals on committees, domineering and patronising attitudes, and failure to take consumers or their views seriously. Several respondents, particularly consumers, said that they had encountered such difficulties.
In Westhill MIND there was a general desire for more consumer involvement, and less professional involvement, which occurred soon after the period of fieldwork. In contrast, several Eastvale MIND respondents said they would welcome more professional participation (83).

**POWER**

Many of the facilitating and hindering factors mentioned by respondents related to issues of power (84). These included perceived inequalities between National MIND staff and volunteers, barriers between consumers and other participants, and the reluctance of the latter to accept shifts of power. There were mixed views about whether the proposed organisational changes would bring about such shifts. Whilst some respondents were optimistic about this, a minority, particularly MIND staff, questioned whether some participants really wanted consumers to have increased power, and referred to ulterior motives, such as a wish to be seen to be interested in consumer involvement because it was "fashionable" (85).

The existing power of some "non-consumer" members of MIND, particularly professionals, was said by some to inhibit consumer involvement, particularly in Westhill MIND. However, facilitative attitudes of professionals and others were also described, particularly in Local Associations with high consumer involvement. Some respondents described feelings of powerlessness when they were psychiatric inpatients, but felt that involvement in Local Associations had resulted in gains in power for themselves and other people with consumer experience (86).
Almost all respondents said that they were in favour of increasing consumer involvement in MIND, but few felt that the organisation should be entirely consumer run. This reflected respondents' recognition that MIND was concerned with professional and public interests, as well as those of consumers. Some National MIND staff felt that MIND could best encourage consumer involvement by assisting the development of autonomous structures and organisations for this purpose (87).

MIND's history also appeared to limit consumer involvement. In contrast with the other voluntary organisations studied, it had developed from a beneficent organisation, largely run by professionals, laypeople and politicians.

Several authorities state that the effective growth of participation depends on clearly formulated policies and objectives. During the period of fieldwork, there were a number of National MIND policy proposals for developing and increasing consumer involvement throughout the organisation. These included the Consumer Advisory Network, changes in structure and accountability, and initiatives to increase accessibility of the organisation to women and people from black and minority ethnic groups (88).
These proposals all eventually because policies which were implemented, but most respondents felt that National MIND did not have clear objectives for consumer involvement. A few respondents questioned the commitment of some participants to implement this, rather than just talk about it. Many were unsure how consumer involvement could best be achieved. "Through Local Associations" and the Consumer Advisory Network were mentioned most frequently, although some respondents felt that the latter would marginalise its members or be unrepresentative of all consumers. Also mentioned were insufficient opportunities for consumers to participate in formal policy making or be employed by Headquarters, even though National MIND had an equal opportunities policy related to people with mental health problems, and had proposed that Local Associations should adopt this.

RESOURCES AND ORGANISATIONAL COMPLEXITY

Lack of time was mentioned by some consumers as a reason for not wanting to participate in National or Regional MIND, and by a few other respondents in relation to giving individuals with appropriate training to enable them to participate. The importance of providing relaxed, informal environments, democratic relationships between consumers and other participants and opportunities for discussion were also stressed by several participants as facilitating factors. The formation of cliques and lack of equality between participants was said by many respondents to hinder consumer involvement (89).
Several respondents felt that consumer involvement was hindered by organisational complexity. For example, decision making needed specialised and expert knowledge in Westhill MIND and other Local Associations which provided a wide range of services. Accountability to funding bodies was also described as a hindering factor (90).

Communication was mentioned by several respondents. Opportunities for consumers to contribute ideas, e.g. through open meetings, were stressed by many individuals, especially in Eastvale MIND. However, difficulties relating to the complexity and formality of meetings were also often described. Westhill MIND participants tried to overcome this problem through the formation of a number of subgroups in which consumers could participate (91).

The language used in meetings and in National MIND literature was also described as hindering consumer involvement. Some participants referred to factors concerned with the organisation's "image", such as its size, the address of Headquarters, and location of buildings at National and local levels (92).

ACCOUNTABILITY, AIMS AND COMMUNICATIONS

An examination was made of the extent to which participants were able to influence consumer involvement in levels of the organisation other than the one in which they were involved. The relationship between National/Regional MIND and Local Associations more closely resembled
Rhodes' description of central - subcentral government relations than relationships between different levels of a bureaucracy (93) National/Regional MIND had difficulty in influencing Local Associations because of the autonomy of the latter as separate charities, which often had very different aims to those of Headquarters. However, there was some inter-dependence between national and local levels, with the former depending on Local Associations to increase consumer involvement, participate in national campaigning activities, and provide services, both as instances of exemplary advocacy, and possibly to attract funding.

There were few resources which National and Regional MIND could use to increase consumer involvement in Local Associations, other than personal influence. However, whether this was effective depended on the extent to which local participants were aware of, and agreed with, aims and policies (on consumer involvement and other issues) at other levels of the organisation; and the amount and quality of contact and communication with Headquarters and the regional office. Problems of communication and limited contact were often described, especially in Westhill MIND Data from interviews suggested that all these factors varied considerably amongst different Local Associations, and that this limited the extent to which National and Regional MIND staff were able to influence consumer involvement and other matters at local level. In particular, some Local Association participants disagreed with National MIND campaigns, particularly if they (the participants) were providing services for, and receiving funds from, local statutory authorities.
Most respondents thought that the proposed changes in structure and accountability would result in only a slight increase in National MIND's influence on Local Associations.

**STAFF PERSONAL INFLUENCE**

Respondents indicated that the role of National and Regional MIND staff was particularly important in influencing consumer involvement (94). Ideas for increasing this were mooted at a staff policy conference in 1984, and it was staff who gave the impetus to the Consumer Advisory Network, a workshop for Local Associations on consumer involvement and an Annual Conference which facilitated the participation of service users. In addition, National MIND staff proposed the changes in structure and accountability, (partly to further consumer involvement), and facilitated the latter through training events and increasing accessibility of the organisation to women and members of black and minority ethnic groups. Proposals for increasing consumer involvement in Local Association Executive Committees came from a former Assistant Director, although once an Association was established, it was difficult to ensure that it had adequate representation of consumers (95).

Because of Local Associations' autonomy, the personal influence of staff, especially at regional level, was particularly important in effecting consumer involvement and other changes in Local Associations. Ways in which regional staff tried to facilitate consumer involvement included building up good personal relationships, making themselves readily available to consumers and other participants, and enabling them to consider the needs of consumers. Some regional staff said they gave less
credence to the views of participants in Local Associations with little consumer involvement (an indirect form of influence), and some said they used covert means, such as getting people to do things "without their realising it".

**LOCAL ASSOCIATIONS' INFLUENCE ON NATIONAL MIND**

Most respondents felt that Local Associations' influence on National MIND was "slight", and less than half felt that the proposed changes in structure and accountability would increase this. Several National MIND staff described ways in which Local Association participants influenced their work, although this tended to be indirect, rather than through systematic contact (96).

Most Eastvale and Westhill MIND participants felt that the influence of day centre and club members was "nil", or said "don't know". Many day centre members said they would like to participate in National or Regional MIND, although some were unsure of ways in which to be involved. In contrast, consumers in Local Associations with high consumer involvement expressed little interest in participation in other levels of the organisation. There were few attempts, at local level to influence consumer involvement in National or Regional MIND. Only a quarter of respondents thought that the changes in structure and accountability would result in more than a slight increase in consumer involvement.

The following and final chapter considers implications of the study for voluntary and statutory organisations.
CHAPTER 16

IMPLICATIONS OF THE FINDINGS

This final chapter examines some implications of the findings of the study for the effective facilitation of consumer involvement in voluntary organisations in general. Recommendations may also have relevance to statutory services.

Caution is always needed in generalising the findings of social science research to other organisations or situations (1), and the comments which follow should be seen as tentative. However, they are based not only on the findings of the present study, but on my personal experience of, and reading about, a range of statutory and voluntary organisations.

For the sake of clarity, this Chapter includes statements which are sometimes unqualified and prescriptive.

SUMMARY OF RECOMMENDATIONS

It is suggested that, in order for voluntary organisation participants to effectively implement consumer involvement, the following factors need to be considered:
* 1. The type of voluntary organisation.

* 2. Assessment of the need for consumer involvement.

* 3. Which participants will be involved in making decisions about consumer involvement.

* 4. The consequences of consumer involvement to all participants.

* 5. The nature and complexity of consumer involvement.

* 6. The limits of such participation.

* 7. The benefits and problems of consumer involvement.

* 8. Factors likely to facilitate or hinder consumer involvement, including the following items:


* 10. Participants' attitudes and skills.

* 11. Organisational structure.

* 12. Goals, aims and policies.

* 13. Resources needed.

15. Influence and leadership.

Each of these will now be considered in turn.

1. THE TYPE OF VOLUNTARY ORGANISATION

It is suggested that the first step in increasing consumer involvement in an already existing voluntary organisation is for its participants to examine its past, present and future. This involves considering such questions as:

* What type of voluntary organisation has it been in the past?

* What are its features at present?

* What does it wish to become in the future?
(Such questions are similar to those raised by a Regional Director in an objective - setting exercise for members of Southbury Association for Mental Health: described in Chapter 14 (2).

Examining the organisation's history may be of value because this may influence the extent and nature of consumer involvement. For example participants in a formerly beneficent voluntary organisation, may need to consider ways to make it more accessible to consumers. The nature of voluntary organisations - their history, present and future plans - can be understood with reference to various typologies, such as those produced by Gerard, Brager et al and Oliver (3). These are summarised in Table 16.1, P(4).

It should be emphasised that this classification represents "ideal types" of voluntary organisations, and many organisations have mixed features. Thus, data from interviews and literature indicated that, at the time of fieldwork, the National Schizophrenia Fellowship was characterised by considerable reciprocity; but the attitudes of respondents towards "sufferers" appeared beneficent. In addition, the organisation's campaigning activities, and the collective wish of relatives to change Government policies indicated solidarity.

The data from this study indicated that MIND was particularly complex, and had developed from a beneficent charity to an organisation in which consumer and relative involvement had increased from the sixties. Whilst there was some beneficence, mainly at local level, during the period of
Table 16.1
Types of Voluntary Organisation

<table>
<thead>
<tr>
<th>TYPE</th>
<th>FEATURES</th>
<th>RELATIONSHIPS</th>
<th>AIMS</th>
<th>EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. BENEFICENT (Gerard) CHARITY: Leadership or Professional Expertise (Brager et al) PARTNERSHIP/PATRONAGE (Oliver)</td>
<td>Provides services for a client group.</td>
<td>Donor-recipient, with one individual (who sees self as &quot;well&quot;) giving to another who is seen as &quot;ill&quot; or &quot;handicapped&quot;.</td>
<td>To give to people who are seen by donor as less fortunate.</td>
<td>National Association for Mental Health until early seventies. &quot;Southbury Association for Mental Health&quot; (Chapter 14)</td>
</tr>
<tr>
<td>2. RECIPROCITY (Gerard) PARTICIPATION (Brager et al) CONSUMERIST/ SELF HELP (Oliver)</td>
<td>Mutual aid/self help. People meet together to both give and receive help and support.</td>
<td>Egalitarian. All participants are both &quot;helper&quot; and &quot;helped&quot;.</td>
<td>To give and receive mutual aid.</td>
<td>Fellowship of Depressives Anonymous. Manic Depression Fellowship. National Schizophrenia Fellowship.</td>
</tr>
<tr>
<td>3. SOLIDARITY (Gerard) PARTICIPATION (Brager et al) POPULIST/ ACTIVIST (Oliver)</td>
<td>Activities to raise conscious and shared identity amongst members; and to radically change attitudes and social structures.</td>
<td>Egalitarian. Awareness of shared difficulties and oppression.</td>
<td>To radically reshape societal attitudes. In some cases, to overthrow existing social and political systems.</td>
<td>Campaign Against Psychiatric Oppression. Some of the organisations affiliated to Survivors Speak Out.</td>
</tr>
<tr>
<td>4. MIXED (Features of two or three of the above)</td>
<td>Varied. Provides services for (but some extent with) consumers. Also includes self help and campaigning.</td>
<td>Changing from donor - recipient to relationships characterised by reciprocity and solidarity. Mixed membership of consumers, laypeople and professionals.</td>
<td>Complex, related to aims listed above.</td>
<td>MIND from early seventies to present.</td>
</tr>
</tbody>
</table>

Based on:
- Findings of the present study.
fieldwork, there was also much mutual support and some features of solidarity, with a minority of respondents expressing a desire to radically reform or even overthrow the mental health system. Of the voluntary organisations studied, Campaign against Psychiatric Oppression had the greatest extent of solidarity, and one Local Association studied in preliminary fieldwork (Southbury Association for Mental Health), and other Associations described by respondents, showed features of beneficence. According to respondents, these organisations were largely professionally-dominated, with little consumer involvement, and a tendency to provide services for consumers, rather than with them.

2. ASSESSING THE NEED FOR CONSUMER INVOLVEMENT

Perhaps the first questions to be asked, in considering whether or not there should be more consumer involvement in an organisation, are:

* Is consumer involvement necessary?

* If so, why?

* Who wants consumer involvement?

* Do the other members of the organisation also want consumer involvement?
Whilst there appears to be increased support for the notion of "charity" from the political right (5), more radical views of voluntary activity tend to strongly criticise beneficent organisations, and to stress the benefits of participation (6). However, the notion of participation involves a paradox which does not appear to have been examined in much of the literature: viz, should participatory structures be provided for consumers if they do not wish to participate? Some consumers may choose to become members of beneficent organisations which provide services for them, and may not wish to be involved in the decision making process (7).

Enthusiastic proponents of consumer involvement need to check that their views are salient to other participants (8). A study by Cumming and Cumming found that medical staff failed to effect lasting changes in a psychiatric hospital because of the continued opposition of nursing aides, who were not consulted (9). Similarly, consumer involvement is unlikely to be effectively introduced without the agreement and support of at least some participants.

It is suggested that it is important to consider the views of all members of the organisation and the reasons for opposition to ideas to increase consumer involvement. These are likely to be threatening to members of organisations which are beneficent, and/or whose members have entrenched attitudes and ways of working. Many consumers may not wish to participate because they are used to professionals making decisions for them, and
continue to prefer this. Many people from long stay institutions may, at first, be unused to being involved in decision making, but have a greater wish for this when living in non-institutionalised milieux, where they have more choice.

If consumers do not wish to participate, it is suggested nevertheless, that it could be considered whether it is worth providing opportunities for information, consultation or expressing views; and making it clear that these are available if they are ever needed. In Eastvale MIND there were many opportunities to participate, but day centre members, (who included some people discharged after many years of institutionalisation) did not have to be involved unless they wished. Nevertheless, interview data indicated that eventually, almost all members chose to participate in some way in decision making and responsibility in the centre (10).

3. WHO MAKES THE DECISIONS ABOUT CONSUMER INVOLVEMENT?

It is suggested that proponents of consumer involvement need to consider who should be involved in decisions to implement it, and this may depend on the proposed extent of consumer involvement in the organisation. If, like MIND, an organisation has largely autonomous local associations or branches, the latter would be able to make their own decisions about participation; but consumer involvement at all levels of an organisation could not, presumably, occur without the agreement of the governing body.
4. CONSEQUENCES OF CONSUMER INVOLVEMENT TO OTHER MEMBERS

The possible consequences (both intended and unintended) (11) of increasing consumer involvement also need to be considered: in particular, whether this will result in less involvement, and perhaps, less power, of other participants, e.g. staff members and professional and lay volunteers. Ways of effecting changes in participation will need to be considered. It needs to be clear who will make decisions, if necessary, to go ahead with consumer involvement if there is opposition to it. Unless there is a revolutionary "takeover" of the organisation by consumers, an evaluation would need to be made of the extent to which other participants are prepared to reduce their involvement. Adequate opportunities for discussion and expression of feelings about this appear to be important. Some psychiatrist pioneers of therapeutic communities have written accounts describing how they implemented changes in social milieux by enabling nurses and other staff to share feelings and explore changes in their role, and the advantages and problems of increasing patient participation in the running of wards. Indeed, support and open communication amongst staff is an important prerequisite; to the setting up of therapeutic communities (12); and, it is suggested, of consumer involvement in voluntary organisations.
5. THE NATURE AND COMPLEXITY OF CONSUMER INVOLVEMENT

In chapter 15 it was concluded that the effective implementation of policies for consumer involvement depends on the recognition that it is a complex, multi-faceted phenomenon (13) consisting of differences in: degrees and levels; components, types and methods; and modes of intervention. In addition, a variety of possible participants may be involved, and the amounts of openness, consciousness and formality can vary.

Findings of the study suggest that, unless consumer involvement is very informal, it needs careful planning. Consideration needs to be given to:

1. The level of formality. If consumer involvement is informal (as occurred in Westhill MIND's social clubs), planning would seem to be inappropriate. (This was certainly the view of many club members in the study) (14).

2. Degrees of consumer involvement from the giving of information to total participation in all decisions and responsibilities in the organisation.

3. Levels of consumer involvement, ranging from the individual's decisions about use of services to attempts to influence central government.
4. **Components, types and methods of participation:** particular ways to involve consumers in decision making and responsibility, and areas in which they participate.

5. **Modes of intervention,** with a consideration of whether this should involve co-operation or conflict with other participants and outside authorities.

6. **Types of participant:** a consideration of which people are to be regarded as the organisation's consumers.

7. The extent to which consumer involvement is **covert** or **overt** ("openness"), with consideration of whether the organisation intends to advertise itself as one which encourages the participation of consumers.

8. Openness is related to the extent that consumer involvement is **conscious** or **unconscious:** Whether the organisation sees consumer involvement as an end in itself, or as a means to achieve an end.

**LEVELS AND DEGREES**

It is suggested that consideration of all these dimensions of participation will enable members of an organisation to be aware of what they are trying to achieve in relation to consumer involvement. Although a few revolutionary psychiatrists, such as Maxwell Jones, have managed to
introduce sweeping changes, leading to increased patient participation (15), it is suggested that increases in consumer involvement are often more easily achieved incrementally. For users of a service who have been cared for in long stay institutions, with little choice, opportunities to participate may be bewildering. They may feel more comfortable if consumer involvement is introduced at the individual level, with opportunities to make choices and decisions about their lives. In addition, it may be easier for such people, at least at first, to participate through information and consultation processes, rather than through direct involvement in decision making and responsibility in the running of an organisation. Eastvale MIND is a good example of an Association where various levels and degrees of consumer involvement were available, but no one was pressured to participate if they did not wish to (16).

**COMPONENTS, TYPES AND METHODS**

It is also important to consider the most effective ways in which consumer involvement can be achieved. This could be through a variety of means, including meetings for the expression of consumer views; consumer satisfaction studies; enabling self advocacy; representation of consumers on governing bodies. The most appropriate area(s) of consumer involvement could also be considered, including campaigning, service provision, fund raising, and other aspects of the organisation's work.
MODE OF INTERVENTION

It is suggested that the mode of intervention (to use the term of Brager et al (17) should also be considered. For example, is consumer involvement to take the form of co-operation or conflict with professionals, or both? Some MIND staff felt that a certain amount of conflict resulting from consumer involvement was healthy and to be expected, although a few respondents expressed reservations about this (18). Non-consumer members of organisations need to ask themselves: "will we mind if consumers use their opportunities to participate to criticise us?" "What will be our response if they want their involvement to go to higher levels and degrees than we would like?"

TYPES OF PARTICIPANT

It is important to consider which people are considered by the organisation to be "consumers", and encouraged to participate. E.g. in a voluntary organisation for mental health, it needs to be decided whether "consumers" include relatives of people with mental illness, all members of the public as potential users of services, people who have experienced oppression as compulsorily admitted inpatients, and willing recipients of outpatient psychotherapy.
In addition, it is suggested that the organisation needs to be clear about the particular people it aims to represent. For example, if it is concerned to advocate the needs of all members of a specific client group through campaigning, it is important to ask to what extent consumers involved in this activity adequately represent their constituency. (E.g. can white, male, middle class consumers speak for those who are black, female or working class?) The organisation could also consider ways of involving consumers who are not members of the organisation: for example, through a consumer satisfaction study of local users of services.

OPENNESS AND CONSCIOUSNESS

There are also advantages in deciding whether the organisation wishes to encourage consumers to share their experiences or not, and the reasons for this. E.g. it might be considered stigmatising to differentiate between "consumers" and "non consumers", a view of some Council of Management members in the present study (19). It was found that there was both "conscious" and "unconscious" consumer involvement in MIND. An organisation whose members felt that identifying consumers was stigmatising might prefer unconscious participation which is unplanned and "just happens". On the other hand, if the involvement is conscious, the sharing of consumer experience may raise individuals' consciousness, self-esteem and sense of empowerment, and attract more consumers to the organisation.
LIMITS OF CONSUMER INVOLVEMENT

The limits of consumer involvement also need careful consideration. Some critics have commented that certain therapeutic communities do not involve "real participation" because staff are ultimately in control of decision making (20). It is suggested that it is important to clearly articulate the limits of consumer involvement, where necessary. It also needs to be determined who decides on these limits, and whether consumers are involved in this.

7. PERCEIVED BENEFITS AND PROBLEMS

The goals of consumer involvement are related to its perceived benefits. It is suggested that consumer involvement will be more readily achieved if participants are not only aware of potential benefits, but endeavour to anticipate any likely problems. This may enable members to be more prepared, to develop strategies for dealing with difficulties effectively. For example, problems to the organisation caused by consumers' difficulty in participating because of illness could be obviated, as in the Manic Depression Fellowship, by having "shadow" committee officers, who can relieve the main officers, when necessary (21). The problem of decreases in consumers' self esteem because of their difficulties in participating in formal meetings could be ameliorated either through appropriate training, or through making meetings more accessible to consumers (22).
It may be necessary to consider whether the benefits of consumer involvement outweigh the disadvantages: e.g., whether increased consultation of all consumers will result in delays in decision making, or opportunities for open discussion result in more criticism of the organisation, - and whether or not this matters.

**8. FACILITATING AND HINDERING FACTORS**

It is suggested that it is also important to be aware of factors which may facilitate or hinder consumer involvement. These include:

1. The role of particular participants eg. volunteer consumers, lay people, professionals, and paid staff.

2. Organisational factors, including structure and communication.

It is suggested that self awareness is an essential prerequisite for the achievement of consumer involvement, with all participants being aware of their own attitudes to consumers, and beliefs about the latter's ability to participate. This includes awareness of the existence of mentalism or disablism: prejudiced attitudes towards people who are perceived as having mental health problems or disabilities, including assumptions that they are helpless or need others to make decisions for them. Consumers, themselves, may hold such attitudes (23).
A first step in enabling consumers to participate is for them to feel valued and empowered. This can be achieved, in part, through the image projected by the organisation, and it may be helpful for participants to examine this: something currently being done by the Spastics Society, following criticism by people with cerebral palsy (24). Does a particular organisation represent clients as helpless, emphasising their differences from other people, and their need for charity, – or depict them as people who are empowered, with much to give others? The image of the organisation will either indicate that it is a charity working for clients, or that it works with them, or consists of them (25).

Much of the literature suggests that consumers are more likely to feel valued if services offer them choice, and respect their dignity and individuality, and their unique needs, including those related to their culture, gender and sexuality (26). Consumer involvement is unlikely to be effective in services which do not meet such needs.

Another important prerequisite of effective consumer involvement is the image which consumers have of themselves. People with low self-esteem, who feel stigmatised, are likely to find it harder to participate than those with positive self-images. A number of writers refer to the importance of raising consciousness, and development of a sense of personal and group pride, identity and solidarity as enabling participation amongst people who have experienced oppression: including those who have survived coercive and insensitive services and processes of labelling and stigmatization (27).
10. PARTICIPANTS' ATTITUDES AND SKILLS

Findings of the present research indicate that both consumers and non-consumers can facilitate consumer involvement through fostering and reinforcing consumers' positive image of themselves. This can be achieved through being prepared to listen to consumers' views and to learn from them, which requires the provision of adequate structures for consumers to share views and experiences. A striking finding of the study is the difficulties which professional volunteers, in particular, had in not dominating decision making, in terms of their own predominance in number on Committees, and their own readiness to participate. Examples were given of the refusal of some professionals and laypeople to listen to consumers' views, and their assumptions that consumers were unable to participate. Paternalistic attitudes hinder consumer involvement. Equally, the willingness of professionals to learn from consumers, consider their perspectives, and take a conscious decision not to be controlling were said to be facilitative (28).

It may be helpful to assess the extent of skills and experience (and their lack) which consumers and other participants bring to the organisation, and to consider ways in which these can be used to facilitate further consumer involvement. Where necessary, appropriate training could be provided for consumers and other participants.
11. ORGANISATIONAL STRUCTURE

The findings of the study also suggest that consumer involvement can be more effectively facilitated if organisations examine whether their structures hinder participation, and if so, to consider whether these are really necessary. It may be decided that certain structures (eg. committee meetings) can either be changed to enable participation; or that they are necessary for the efficiency of the organisation, even though they are inimical to consumer involvement. If the latter is the case, separate structures, such as open meetings or subcommittees could be provided (as in Eastvale and Westhill MIND) (29), so that as many consumers as possible can participate.

Consideration could also be given to the language used in meetings which, if "middle class", or involving jargon, may prevent particular consumers, and other participants, from becoming involved. The language in the organisation's literature can also facilitate or hinder consumer involvement, depending for example, on whether it is accessible to potential members of ethnic minorities, and to working class people.
12. GOALS, AIMS AND PRIORITIES

It is suggested that it needs to be clear to participants whether consumer involvement is a separate goal, or inherent in various goals of the organisation. If the former, it is important to examine the extent to which it is likely to conflict with, or complement other goals or ways of achieving them. E.g. is increasing consumer involvement likely to lead to more or less organisational efficiency? To what extent will it result in more time being taken to make decisions, and does this matter?

In addition, members of the organisation may feel (as did most MIND respondents), that there is also a need for (non-consumer) leadership, and for professional expertise. It is suggested that there is a need to weigh up the relative needs for participation versus leadership and professional expertise (30), (although of course, consumers may have these qualities). If like MIND, the organisation serves a wide range of professional and public, as well as consumer interests, it is also necessary to consider the extent to which it needs the participation of people other than consumers.

Unless it is intended that the consumer involvement will be informal, covert or unconscious, it is suggested that it is important to formulate clear goals and policies, both in terms of what consumer involvement is intended to achieve, and for particular methods of implementation. Data from the research suggests that policies, or at least, outlines of the goals of consumer involvement, need to be readily accessible to all participants. These will help to clarify the purpose of participation, and what it is that people are working to achieve.
In some cases, consumer involvement may be seen as a good in its own right. Other goals may include intrinsic benefits to consumers, such as increased empowerment or self esteem, and benefits to the organisation, such as service provision which is responsive to consumer need.

In addition, data from the present study suggest that clear policies about the means to achieve consumer involvement also assist its implementation.

13. RESOURCES

The effective implementation of policies and goals for consumer involvement depends on adequate resources. It is suggested that the organisation needs to be aware of the resources which will be needed to facilitate consumer involvement. These may include increased commitment from different participants; increased time to pass on information, or consult with consumers, or possibly, to make decisions; training e.g. to enable consumers to be involved in participatory processes. Extra funding may be needed: e.g. so that participants can travel to workshops or meetings on consumer involvement. Additional rooms for meetings and other facilities may also be required.
14. COMMUNICATION AND RELATIONSHIPS

Data from the present study indicate that communication and relationships amongst participants also have an effect on consumer involvement. If these are poor, the influence of particular individuals is likely to be reduced. Where this is the case, examination of ways in which communication can be improved is likely to be of help. Good communication can include opportunities to share ideas about participation, e.g. through meetings and workshops, and the dissemination of newsletters and other literature which include examples of consumer involvement, and how this was achieved. In addition, a milieu where all participants feel supported, and able to share ideas, feelings and problems, is likely to promote consumer involvement (31).

15. INFLUENCE AND LEADERSHIP

Finally, it needs to be clear which participants have the power to encourage the development of consumer involvement, and ways they can exert influence to achieve this. Direct authority, and the use of particular resources (e.g. informational, financial) may be used, but are likely to have a limited place (32), especially in a large national charity with local autonomous associations or branches (33). Personal influence is likely to be the main means to facilitate consumer involvement, and in MIND this was found to be a crucial factor (34). Findings of the study indicate that personal commitment to consumer involvement, from both members and leaders of the organisation, is also important, as was the case in MIND (35).
This study has attempted to look critically at the nature of consumer involvement, and has tried to examine benefits and problems, facilitating and hindering factors. I am very grateful to my research supervisors, to many participants in MIND, and the other voluntary organisations studied, and other people who were interviewed, for enabling me to come to a better, and perhaps, more objective, understanding of the concept. But the work for this thesis has involved feelings, as well as rationality. I have been impressed, and sometimes inspired, by the many people who have used their own experience to give to others facing similar distress and problems, and by the commitment of so many people to facilitate consumer involvement. I hope this thesis will be a small (if rather long!) contribution.
NOTES TO CHAPTERS
CHAPTER 1 - NOTES


4. These terms are discussed in Chapter 3.

5. See Chapter 3, p 52.f.


10. These points are examined in Chapters 4, 5 and 6.

11. The issue of values is explored in Chapter 2.

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12. Levels and degrees of consumer participation refer respectively, to the extent, attempted and actual, of consumer participation: from involvement in individual care and treatment to central government policy making; and to the amount of influence or power possessed by consumers, ranging from nil to complete control. These ideas are developed in Chapter 3. See particularly p 49 f.

13. The Mental After Care Association is the oldest extent voluntary organisation for mental health, having been founded in 1879. (JONES, K. 1972. A History of the Mental Health Services, p 236). MIND, founded in 1946 as the National Association for Mental Health, appears to be the second oldest.

14. I was aware of the formation of the Mental Patients' Union, which campaigned for patients' rights in the early seventies, but was unsure whether any patients' rights movements existed in the U.K. at the time I started my study.

15. This is discussed in more detail later in Chapter 5.

16. This organisation became known as the Fellowship of Depressives Anonymous in 1986.

17. I am very grateful to Chris Heginbothan, former National Director, Lord David Ennals, former Chairperson of the Council of Management, and other MIND participants for so readily agreeing to the study; and to William Bingley and Sheena Dunbar, former Assistant Directors, for their help in various ways.

18. A list of all the respondents interviewed is given in Table 2.1, p 24.

19. Here, as elsewhere, pseudonyms are used.

20. I am very grateful to Rae Husein, former Local Associations Co-ordinator, for her help in many ways.

21. As will be seen in Chapter 7, the last two categories tended to overlap.

22. A few "stage 3" interviews were conducted before and after this date.


24. See Chapter 3, p 49 f
CHAPTER 2 - NOTES


4. See Chapter 1, p 23f.


9. These, and other problems of participant observation are outlined in MOSER, C.A. and KALTON, G. 1971, op cit, p 247 f.


12. Two staff members moved from a National MIND department to a newly created Region just after the period of fieldwork. They have been counted as "regional staff" as most of their work was concerned with regional matters, even when they were based at Headquarters. Respondents interviewed in other voluntary organisations were as follows:
Campaign Against Psychiatric Oppression 3
Depressives Anonymous 3
Manic Depression Fellowship 3
The Matthew Trust 1
National Schizophrenia Fellowship 4
O'ran's Trust 1

13. These included one National MIND volunteer, two Eastvale MIND day centre members, and a few MPs for the Eastvale and Westhill areas.


15. There are variations in the number of respondents who answered such questions because of the lack of structure to interviews.


18. This difficulty was immediately discussed with my research supervisor, Professor A. Webb, who suggested that I offer to discontinue my fieldwork in the Local Association. This was suggested, but participants indicated that they did not mind if this continued.

19. Respondents were chosen at random from three groups: stewards, those who had other responsibilities at the time of interview, and those without such responsibilities. In addition, all day centre members who were serving on the Executive Committee, were selected for interview.

20. Other reasons for choosing MIND for a study of consumer involvement are outlined in Chapter 1.


22. Issues concerning values are further discussed in Chapters 1 and 15.


6. Ibid.


9. Ibid.


15. GOCDER, 1976, op cit, p127f.


22. Ibid, p63f.


33. Ibid.


35. DRAPER, P. et al, op cit, p 286.


40. These publications are mentioned later in this chapter on p 42.

41. KING, D., 1987, op cit, p 56.


44. DHSS 1983, op cit.


49. KING, D. 1987, op cit, p 56.


52. Patient satisfaction studies of mental health services include those listed in Note 30 of this chapter.


56. This legislation is considered in more detail later in this chapter on p <57>.


64. This is further considered later in this chapter, on p 57 F.


HOUSE OF COMMONS 1985b. The Government Response to the House of Commons Select Committee on Community Care for the Adult Mentally Ill and Handicapped. Nov. 1985, Cmd. 96 74. Quoted in source which I did not note at time and cannot trace.


For an example of consumer participation in local mental health services, see: KING, D. 1991. Moving on from Mental Hospitals to Community Care. London. The Nuffield Provincial Hospitals Trust.

69. NATIONAL COUNCIL FOR VOLUNTARY ORGANISATIONS. 1984, op cit, p 7f. SMITH, J. 1987 "Social Services". Chapter 8 in CLODE, D. et al (Eds.) 1987, op cit, p 75f. See p45f of this thesis for a more detailed consideration of these and similar terms.

71. SHAW, I.F. 1984, op cit, p 278.
73. SHAW, I.F. 1984, op cit, p 278.
74. SMITH, J. 1987, op cit.
78. SMITH, J. 1987, op cit, p 76.
80. On p39f of this Chapter.
84. NATIONAL COUNCIL FOR VOLUNTARY ORGANISATIONS, 1984, op cit.


93. See Chapter 6.


108. See Chapters 6 and 7.


114. "Relative involvement" is not a term much used in the literature.


119. ROSE, H. 1976, op cit, pp 67 and 69. Rose notes that the term "involvement" is also ambiguous.


121. FOWLER, P.R. 1987 a, op cit, p 14.


123. FOWLER, P.R. 1987 a, op cit. See chapter 6 of this Thesis.


130. Ibid, p 123.

131. Ibid, p 118. These and other factors will be examined in Chapters 8 and 9 of this thesis.


141. ROSE, H. 1976, op cit, p 63f.

142. ARNSTEIN, S.R., op cit, p 216.


151. Ibid, p 3.


160. SEEBOHM, F 1968, op cit, para 137, p 43.

161. Ibid, para 491, p 151.
167. Ibid.
170. This is described in the section on consumerism earlier in this chapter (p37f).


Seebohm, F. 1968.

Ibid.


Holland, P.F. 1978, op cit, p 197.


Richardson, A. 1983, op cit.

Ibid, p 102f. Chamberlin indicates that increased awareness of oppression and unsatisfactory conditions can lead to an increase in patient participation (Chamberlin, J. 1988, op cit).

Richardson, A. 1983, op cit, p 101 f.

Ibid, p 108 f.


This is indicated, in part, by an apparent growth of research into consumer views of services.


Ibid, p 112.


DYER, 1985, op cit, p10.


RICHARDSON, A. 1983, op cit, p 117.


ARSTEIN, S. 1969, op cit.

RICHARDSON, A. 1983, p 70.


RICHARDSON, A. 1983 op cit p 118f.
222. COOK, T. 1987, op cit, p 15. GRAYCAR, A. 1979, op cit, p243
225. See p 175f.
230. Ibid, op cit, p 171.
231. Ibid, p 175 f.
232. Ibid, p 179.
235. RICHARDSON, A. 1983.


244. SMITH, L. 1983b, op cit, p 94.
254. See Chapter 3. p 72 ff.
256. Ibid, p 27.
257. Ibid, p 27.
258. See Chapter 3 p 59 ff.


278. Ibid, p 57.


296. See Chapter 3, p 77.
298. Ibid.
301. BRAGER, G. et al 1987, op cit.
304. Ibid.
305. ROSE, H. 1976; op cit, p 63.
308. Ibid, 269 f.
310. Ibid, p 173.
311. RICHARDSON, A. 1983, op cit, p 94.
312. Ibid, p 94.
313. WINDLE and CIBULKA 1981, op cit, p 11.
316. See Chapter 15, p 479f.
317. See Chapter 7, and Chapters 15 and 16.
318. See Chapter 15, and Chapter 16.
CHAPTER 4 - NOTES


8. The Mental After-Care Association chose to remain an independent voluntary organisation at this time, and subsequently.


13. Ibid.

15. Two of these, serving South West and South East England, opened in late 1985. The other Regional Offices were those for Wales and North West, Northern, Trent and Yorkshire and West Midlands Regions of England.


17. NATIONAL ASSOCIATION FOR MENTAL HEALTH 1960, op cit.

18. Table 4.1 is based on figures given in NAMH/MIND. Annual Reports and Annual Reviews for the appropriate years. Unlike other Annual Reports and Annual Reviews, those of 1946 to 47 and 1977 to 78 do not list all the Local Associations. The 1977 to 78. Annual Review states that there were "over 150" Local Associations in that year.


24. There have been some changes in this structure since the period of fieldwork.

25. The South West Regional office, opened in 1985, did not have a Regional Director until the following year.

26. MIND. Undated a, op cit.

27. This list is based on interview responses to questions about the work of MIND and particular Departments.

28. This is described in Chapter 6.


32. According to MIND's General Secretary in the nineteen fifties: "the fifties were remarkable for our consistent campaigns to persuade people that mental health was OK; that mental illness could be cured, and that the hospitals were very nice places" (APPLEBEY, M. 1974. Transcript of speech given at Oxford.) My thanks to Rae Husein for a copy of this speech.


34. This organisation is now called Mencap.


40. MIND. 1972, op cit.

41. Quoted in ANDERSON, and ANDERSON, I. Undated, op cit. Original source not stated.


44. BINGLEY, Lady J. 1983, op cit.

45. This report subsequently became "A Human Condition", published by MIND in 1975.

46. BINGLEY, Lady J, 1983 op cit.


54. MARTIN, F.M. 1984, op cit.


58. The first two categories in this table overlap but reflect the terms used by respondents.

59. Other main aims (each mentioned once) included: training mental health professionals, appeals, concern for patients' needs and encouraging consumer involvement (all mentioned by the same respondent); community care and housing were each mentioned by one respondent.


64. BINGLEY, LADY, J. 1982, op cit.


66. Ibid.


69. The Policy Committee consisted of Council of Management members and representatives of (senior) staff of all National Departments and Regional Offices. Policy working groups included staff and members of Local Associations and other voluntary organisations.


71. It is difficult to assess how far this difference is, in part because many respondents were more familiar with the MIND of 1985, but it is probably significant that most respondents remembered MIND mainly for its legal work, and did not often mention other aims.

72. HEGINBOTHAM, C. 1985c, op cit.
CHAPTER 5 - NOTES


14. Ibid.

15. JONES, K. 1972, op cit; p236. Dr. Bucknill, an influential psychiatrist, was first president of this organisation.


17. JONES, K. 1972, op cit, p 255.


20. Ibid.


29. NATIONAL ASSOCIATION FOR MENTAL HEALTH. 1964, op cit.


32. NATIONAL ASSOCIATION FOR MENTAL HEALTH. 1964, op cit.
33. MIND 1972. Annual Report, 1971-72. This report includes an account of Local Associations' work which describes them as running projects and services for, rather than with consumers.


35. Some people were referred to the Legal Department by relatives, lawyers and mental health professions.


37. In retrospect, it would have added to the study to have assessed this.


44. BENDER, M. Undated, op cit.

46. Source: interviewing, participant observation, and MIND 1985a, op cit.
The three stages of the fieldwork are outlined in Chapter 1, p 8. The pilot interviews are further described in Chapter 2, p 20.

This and other methodological issues are discussed in Chapter 2.

Consumer involvement in Eastvale and Westhill MIND is described in detail in Chapter 7.

Some respondents at local level were also asked these questions (Schedule 1.3 and 1.4: Appendix 1.1).

Council of Management (the governing body of National MIND), and the staffing of the National and Regional offices, are briefly described in Chapter 4, p 93. Forum was a body of elected Local Association representatives, which met regularly and represented local members' views to Council of Management.

Table 2.1 (p 21) indicates the National and Regional MIND respondents who were interviewed. Not all respondents were asked each of the questions referred to in this chapter.


Schedule 1, Q3. (Appendix 1.1).

Consumer Involvement in the Mental Health Movement, Notes on Workshop for Local Associations held on 16 May, 1985, at the Council House, Bristol. MIND internal document. Some course participants debated the question "who are the consumers?" and I was asked to prepare a discussion paper on this topic. (Appendix 4).

DUNBAR, S. 1985, op cit.

Some respondents gave more than one of these categories in response to the question.

Source: interviews with respondents.

This was possibly partly because of the way the question was worded.

People who were unemployed or trying to find their own solution to problems were each mentioned by one respondent.

Heginbotham, C. 1985b, op cit.
15. Quotations from interviews are taken from notes made at the time. Square brackets enclose words which were not written down at the time, or which have been added or replaced in the interest of clarity.

16. Relatives' perspectives of family members with mental illness is briefly considered in chapter 10, p 339f.


18. There are references to people with learning disabilities in National Association for Mental Health/MIND Annual Review/Reports for the years 1946 - 47 to 1985 - 86. However, work involving these people was being gradually phased out during the period of fieldwork.


20. I have seen this quotation in at least one MIND publication, but am unable to trace its source.


22. MIND 1985a, op cit, p. 2.

23. See Chapter 3, p 38f and 46f.

24. This suggests that an organisation which is attempting to increase "consumer participation" needs to consider whether or not service users see themselves as "consumers" and are familiar with the term.


26. Schedule 1, Q4a (Appendix 1.1)

27. These figures do not include a few respondents whose response was "don't know", but who then gave a definition of consumer involvement.

28. Some respondents mentioned more than one of the categories listed in Tables 6.2 and 6.3. See Chapter 3 p 73f for an account of levels of consumer involvement.

Specific items mentioned in relation to consumer involvement were MIND's Annual Conference (two respondents), MIND publications (four respondents) and a proposed consumer advisory network (four respondents). Ways to increase consumer involvement in MIND are discussed later in this chapter and chapter 12.
29. These will be examined later in this Chapter and in Chapter 7.

30. See Chapter 11, p 267.

31. The issue of power in MIND is considered in chapter 9., p 360 f

32. These problems are considered further in Chapter 2.

33. Respondents were not asked specifically about their views on whether or not participants should make their consumer experience (if any) explicit but several people spontaneously gave views on this during interviews. This issue had been debated in at least one Council of Management meeting, and in a Policy Committee meeting, and is discussed in Chapter 12.


35. MIND 1985a, op cit, and other Annual Reports

36. This is examined in Chapters 8, 10, and 11.

37. Sources: MIND literature, interviews and participant observation.

38. Council of Management members met about six times a year. Staff often met informally and for meetings, but there appeared to be few attempts in National MIND to enable participants to share experiences and feelings.

39. Schedule 1, Q42, (Appendix 1.1). This question was asked only when sufficient rapport had been established with the respondent, and when there was sufficient time. The question was near the end of the interview schedule.

40. These figures include a few respondents who informally mentioned their own experience of mental health problems.

41. Source: interviews. One respondent had received psychotherapy, but his consumer experience did not appear to be the main reason for his involvement.

42. Interview with a Regional Director.

43. Source: non-participant observation notes.

44. Members of the Council of Management, who also gave their time voluntarily, were not described as "volunteers". Of the nine volunteers interviewed, none had been a member of Council of Management, or of any other body concerned with National MIND Departments.
45. The number of volunteers in the National Office during Summer 1985 (when interviews took place) was uncertain, as the organisation did not, as far as could be ascertained, have a list of all volunteers, or one individual to whom they were all accountable.

46. Here, as elsewhere, Local Associations and the towns and boroughs in which they are situated, are given pseudonyms.

47. Source: interviews with volunteers, National MIND.

48. These volunteers were not interviewed.

49. Schedule 3, Q9. (Appendix 1.3).

50. Respondents were not asked directly about such involvement, although schedule 3, Q10b (iii) asked them whether they would like to be a Council of Management member. (Appendix 1.3).

51. The perceived benefits and problems of consumers' voluntary work are considered in Chapters 8 and 9.

52. Source: participant observation. Other comments about Regional volunteers are based on interviews.

53. MIND. Annual Reports 1981-82, to 1985-86.

54. Schedule 1, Q10 (Appendix 1.1.) A few staff members were also asked this question in relation to their own work if this was markedly different to that of other members of their Department. Some respondents were not asked all the question because of limited time for interview.

55. This included the Community Development Department, which was dissolved and mostly incorporated into MIND South East in October 1985. Other Departments included were Appeals, Legal, Policy and Information and Training and Education.

56. The work of this team is described later in this chapter, on p 153. At the time of interview, the team was based in the Community Development Department.

57. Thus, an Organising Tutor evaluated consumer opinion by asking two service users whom he knew, and members of a local Mental Health Consortium which included consumers. A staff member of the Community Development Department asked residents their opinions if there were management problems in the hostels with which he was involved.

58. Only one respondent in each Region was asked this Question because of limited time to interview other respondents.


61. Respondents in three Regions were asked Schedule 5, Q5b (i) and (ii) on Normalisation and Advocacy. The respondent in "Albion" Region (pilot interview) was not asked this question, as it was only after this interview that the possible importance of Advocacy and Normalisation in regional work was realised.

62. This was a contrast to Eastvale MIND (one of the Local Associations studied in depth) and one of the Local Associations with high consumer involvement, in which several consumers were very interested and involved in fund raising activities. See Chapter 7.

63. Policies for employing people with consumer experience are considered in Chapter 12.


65. Source: interview, Assistant Director, Campaigns Unit.


67. In answer to a specific question: "In what ways do consumers contribute to Training and Education activities?"

68. MIND 1985c, op cit.

69. Ibid.


71. 14 National MIND staff, two regional MIND staff, the chairperson of Council of Management in 1985 and his predecessor, were asked Q7 in schedule 1 (Appendix 1.1).

72. One of the proposals for increasing consumer involvement, further discussed in this chapter, p 154.

73. Source: interviews, Council of Management participants.


75. HEGINBOTHAM, C. 1985c, op cit.

76. The main areas of work of National MIND, during the period of fieldwork, are outlined in Chapter 3.
81. Respondents’ ideas about how consumer involvement could best be achieved are discussed in Chapter 12.
82. See Chapter 4, p 103.
83. This is discussed further in Chapter 4.
84. See Table 4.1, p. 92.
85. HEGINBOTHAM, C. Undated, op cit.
86. Ibid.
89. HEGINBOTHAM, C. 1985d, op cit.
91. MIND 1984, op cit.
92. Ibid.
93. Ibid.
95. Source: interviews with members of the Black and Ethnic Minority Mental Health Development Team.

97. Schedule 5, Q 26 (Appendix 1.5).

98. Source: interviews, Regional Director.


101. Ibid.


103. GILL, B. 1985, op cit.

104. This is further discussed in Chapter 12, p 385.

105. MIND 1985a, op cit.

106. Schedule 1, Q8. (Appendix 1.1).

107. Ibid.

108. In response to Schedule 1, Q9. (Appendix 1.1).

109. Schedule 1, Questions 33 and 35 to 3%. (Appendix 1.1).

110. Some respondents who gave ratings on the 5 point scale were not asked to rate whether the consumer involvement was "not enough" "enough" "enough" or "too much".

111. Several respondents gave answers which fell between two categories, e.g. "between slight and fair". In order to simplify tables, these responses have been assigned to the higher category. Average ratings are correct to two decimal places.

112. See Tables 6.4 to 6.9.

113. Source: interview, Council of Management member.

114. See Chapter , p 138f.

115. Levels and degrees of consumer involvement are considered in Chapter 3, p 69f and in Chapters 15 and 16.
CHAPTER 7 - NOTES

1. The Local Associations Coordinator was responsible for correspondence between the National Office and Local Associations, and for advising the latter on matters concerning their constitution and affiliation.

2. These Local Associations were all reasonably accessible, geographically. They included all the Associations affiliated to National MIND, in a sample, selected by myself, of counties in one MIND Region.

3. See Questionnaire, Appendix 2.

4. I.e., a Chairperson, Vice-Chairperson, Secretary or Treasurer.

5. "Westhill" MIND was chosen in preference to other similar Local Associations because it was more accessible geographically.

6. Almost all participants were happy about the study, although one officer of Westhill MIND, who later agreed, was initially concerned when it was mentioned that the National Director had agreed to a study of MIND as a whole. This participant emphasised that Westhill MIND had little to do with the National organisation. The relationship between Westhill and Eastvale Local Associations and National MIND is examined in Chapter 13.

7. More records were examined in Westhill MIND because they were more accessible to the researcher.

8. A few respondents in both Local Associations were interviewed after the main periods of fieldwork (November, 1984 to March, 1985 in Eastvale MIND and February, 1985 to June, 1985 in Westhill MIND). This is indicated where appropriate.


10. Ibid. Reasons for this "crisis point" are unclear.

11. Ibid.

12. This appears to have lessened since the period of fieldwork. See Chapter 15, p 47f.

13. Sources: ANONYMOUS UNDATED, op cit and fieldwork interviews.

14. The role of professionals in facilitating and hindering consumer involvement is explored in Chapter 11.


17. A few Executive Committee members did not often attend meetings or be otherwise involved in the Local Association.

18. All these four social workers were employed by the local Social Services Department, one as a MIND Development Officer to develop Local Associations in the county.

19. At the time, Eastvale had a high unemployment rate.


21. These are described later in this chapter. See p 178 f.

22. Schedule 7, Q1a. (Appendix 1.7).

23. A large number of Westhill Club members said "don't know" to this question.

24. The following were mentioned as aims by one or two respondents in each instance: legal and welfare rights; MIND Tranquillizers Campaign; training for volunteers; fund raising; referring project users to professionals; liaising with statutory bodies.

25. The Annual Report, 1984 to 1985, for Westhill MIND states that the Association has the same aims as other local groups to provide accommodation and day care services, and to be involved in education about mental health and campaigning. (Source: WESTHILL MIND. 1985. Annual Report, 1984 to 1985). However, the Report mentions in detail the Association's services, and does not mention campaigning or public education.

26. This is further examined in Chapter 13.

27. The possible effects of this difference in complexity on Consumer Participation in the Local Association is examined in Chapter 8.

28. Participant Observation notes, 22.11.84.
29. The Local Association was part of the building to the Self Help Team of the local Council for Voluntary service. Several Self Help groups for mental health met there, including local groups of the National Schizophrenia Fellowship, Depressives Anonymous, and Alcoholics Anonymous.

30. Source: Interview with respondent who founded the Club.

31. Source: Interview, Development Worker, Westhill MIND

32. An exception to this was the County MIND Development Officer, who was an employee of the local Social Services Department, and a Westhill MIND Executive Committee member.

33. This may have been because of particular problems of consumer involvement: eg., apathy, negative attitudes. See Chapter 9.


35. The Local Association's two Development Workers both had links with the local University.

36. The course run by Westhill MIND gave volunteers a choice of working with the Local Association, or Social Services, or the local psychiatric hospital.

37. This and subsequent descriptions of consumer involvement are based on participant observation, unless otherwise stated.

38. A record kept for the Manpower Services Commission, so that this body could assess the number of people who used the Centre.


40. A few members of Zeta Club also met in the Resource Centre on Sundays to watch videos.
41. Source: informal conversation during participant observation, and interviews.

42. Schedule 10, Q1 (Appendix 1.10).

43. Of the other respondents, three said that there was not such a distinction and two said that this varied with different people.

44. Consumers' use of their own experience to help other people is considered in Chapter 10.


46. One respondent was not asked this question.

47. These related particularly to a few respondents finding interviews uninteresting or stressful, despite agreeing to interview. These ethical problems are described in Chapter 2.

48. This is further described in Chapter 2.

49. Subsequently, at Westhill MIND's Annual General Meeting in June, 1985, three club members were elected as members of the Executive Committee, and another member, with consumer experience, was elected as Secretary the following year.

50. Open meetings are examined further later in this Chapter, p 204.

51. This is examined in Chapter 8.

52. Consumers' contributions to MIND based on their own experience is examined in Chapter 10.

53. See Chapter 7, p 53 f.

54. This is examined in Chapter 9, p 282 f.

55. This self help group was a separate organisation to Eastvale MIND.

56. The benefits of mutual support are further examined in Chapter 9.

57. At least one respondent confused the Local Association with local Social Services.
58. Four out of five respondents who were asked, said they saw themselves as being members of the Local Association.

59. Source: non-participant observation. Comments refer to the Annual General Meeting during the period of fieldwork.

60. Schedule 10, Q11. Some Eastvale MIND day centre members and Zeta Club members were also asked a similar question. I have erroneously missed including these in other relevant interview schedules in Appendix 1. Only small numbers of respondents were asked this question.

61. This may partly explain my ready acceptance into Zeta Club. The sample of respondents included three people who were social science graduates.


63. See Chapter 11 for participants' comments on this.


65. Participants' views about the benefits and problems of increasing consumer involvement are described in Chapters 8 and 9.


68. However, few club members attended, or said they would like to be Executive Committee members, for reasons which are given in Chapter 9.

69. Source: written account of a staff member. Not cited, in order to ensure anonymity and confidentiality.
70. Schedule 7, Q. 4 (Appendix 1.7). Day Centre members were asked their views on Executive Committee composition, but most club members were not. Most of the latter seemed to have little knowledge of their Executive Committee.

71. These points are considered in Chapter 9.

72. These and subsequent reported views of Eastvale and Westhill MIND participants, are based on interviews, unless otherwise stated.

73. See Chapter 14, p 448.


75. Schedule 7, Qs. 5, 12, 15, 16, 17. Schedule 9, Q. 7 (Appendices 1.7 and 1.9).

76. Once a month the Executive Committee met at the same time as Zeta Club, but in a separate room.

77. Two of these participants rarely came to the centre during the period of fieldwork.

78. Schedule 7, Q5 and Q16, respectively. (Appendix 1.7).

79. Schedule 10, Q. 23. In addition to Club participants, Executive Committee members were also asked this question (Appendix 1.10).

80. Schedule 9, Q. 7a (iii) and (iv). (Appendix 1.9).

81. Schedule 9, Q. 8a (Appendix 1.9).

82. Some respondents mentioned more than one individual. "Other answers", each mentioned by one respondent, included: the day centre subcommittee, another day centre member on the Executive Committee, and day centre members in general.

83. A weakness of the study is that only five Eastvale respondents were asked to rate day centre members' involvement in responsibility. It did not occur to me to assess this until most Eastvale respondents had been interviewed. Of the five Eastvale participants who were asked this question, four rated day centre members' involvement as "marked" or "very considerable".

84. Schedule 8, Qs 14, and 12A, respectively.

85. This respondent's role in the Local Association is not given, in order to preserve anonymity and confidentiality.
86. See Chapter 7, p 216.
87. These factors are considered in Chapters 9 and 10.
88. This is considered in Chapters 9 and 10.
89. Interview, Treasurer, Eastvale MIND.
91. A weakness of the study is that respondents were not asked why this was the case.
92. Schedule 8, Q.11 (Appendix 1.8).
93. These factors are considered in Chapter 9.
94. One of these respondents was involved in allocating statutory funds to voluntary organisations.
95. Views about this are considered in Chapter 9.
96. See Chapter 3, p 64f.
97. I.e, laypeople who did not see themselves as having experienced mental health problems.
98. See Chapter 3, p 489f.
99. National MIND staff also mentioned other Local Association projects which were concerned with the mental health of a whole Community. e.g. a few Associations ran mother and toddler groups to reduce isolation and other problems experienced by mothers. Other projects included a cafe in a main shopping street and a club for unemployed people.
100. [Eastvale MIND]. Undated. (Written in 1984;) Chairman's Report.
102. See Chapter 3, p 69f.
103. One respondent in a Local Association with high consumer involvement said that she felt my attempts to assess consumer involvement imposed some sort of “reality” onto something which no-one in her Local Association thought about in particularly precise terms. (Ways in which the “reality” of consumer involvement may have become distorted through the mediation of the concepts and assessments used in this research are examined in Chapter 2).

105. Whilst the study of Westhill MIND has placed more emphasis on informal participation, in Eastvale MIND there was a bias towards the study of formal involvement, with insufficient consideration of more informal participation.

106. See Chapter 3.


19. Respondents were asked the following questions on the benefits and problems of consumer involvement. Schedule 1, Q. 29 (Council of Management, National and Regional MIND staff and Forum members); schedule 3, Q. 7 (National MIND volunteers); schedule 7, Q. 10 (Eastvale MIND participants); schedule 7, Q. 13 (Westhill MIND Executive MIND Executive Committee); Schedule 10, Q4 (Westhill MIND club members). See Appendices 1.1, 1.3, 1.7 and 1.10. Differences in the wording of these questions are likely to have affected the responses of different groups of respondents.

20. See Table 2.1, p 21, for details of the numbers of respondents interviewed.
Members of the other voluntary organisations studied were asked the following questions: Schedule 12, Q13 (Campaign Against Psychiatric Oppression), Schedule 13, Qs. 7 and 8. (Depressives Anonymous), Schedule 14, Qs. 7 and 8 (Manic Depression Fellowship), Schedule 15, Qs. 11 and 12 (Matthew Trust). Schedule 16, Q.10 (National Schizophrenia Fellowship). See Appendices 1.12 to 1.16.

Regional staff were asked, usually by telephone, which Local Associations: a) were founded, wholly, or in part, by consumers, b) had one or more officers with consumer experience; c) had consumers actively involved in campaigning.


Two Local Associations were chosen for study from each of five of the seven MIND Regions. One Region was said not to have any Associations with high consumer involvement. Another Region had one such Association which was geographically inaccessible.

Other benefits and problems, besides those indicated in Tables 8.1 and 8.2, were mentioned by under six respondents. Benefits included: consumer involvement as a good in itself, and increasing a sense of involvement or belonging (both mentioned by five respondents); having a voice in the organisation (three respondents); and use of skills and abilities, gaining knowledge/increasing horizons, and informality in the organisation, which were each mentioned by two respondents. Four individuals gave lack of help or friendships as a problem, whilst uninteresting activities and other participants' mental health problems were both mentioned by three respondents. The following problems were referred to by one or two individuals: insufficient consumer involvement; lack of salience of each participation; ulterior motives for increasing consumer involvement; preoccupation with mental health problems.
28. Some respondents answered the relevant question by mentioning more than one benefit or problem, or by concentrating mainly on either benefits and/or problems to either the individual consumer or the organisation. For this reason, the total numbers of benefits and problems in Tables 8.1 and 8.2 differ from the total numbers of respondents.

29. This was also mentioned by some respondents in Eastvale MIND.

30. These, and other topics, are examined later in this chapter.

31. Differences in wording of questions probably accounts, in part, for the number of benefits and problems reported.


33. HUGHES, A., op cit, p 54.

34. See Chapter 4, and Chapter 12, p 370 f.

35. This point is considered later in this Chapter.

36. See Chapter 5 for a consideration of this point.

37. Respondents' views on consumer involvement are further described in Chapter 6 (National/Regional MIND) and Chapter 7 (Eastvale and Westhill MIND).

38. Schedule 1, Question 28a (Appendix 1.1).

39. This is discussed in Chapter 9.

40. This is described in Chapter 9 and 10.

41. In their study in mutual aid organisations, Richardson and Goodman found that most members had joined in order to receive help, rather than to participate in the giving of help or the running of the group. (RICHARDSON, A. AND GOODMAN, M. 1983, op cit).

42. This is described further in Chapter 9.
43. See the References listed in Note 32 to this Chapter.


45. These comments are based on data collected from participant observation and interviews.

46. BOADEN, M. et al., 1982, op cit, p 96. GOLDBLATT, H. 1968, op cit, p. 35. HUGHES, A. 1985, op cit, p 53. (Hughes describes participation as "...both a means and an end in itself.").


48. See Chapter 7, p 179.


50. Ways in which the "reality" of consumer involvement may have been distorted through the mediation of the concepts and assessments used in this research are examined in Chapter 2.

51. Source: participant observation notes.

52. This is discussed further in chapter 10.

53. Schedule 9, Qs. 1b and 2 (i). (Appendix 1.9).

54. The source of statements here, and elsewhere in this chapter, is interviews with respondents, unless otherwise stated.

55. The role of stewards is described in Chapter 7, p 181.

56. Nevertheless, overall, Eastvale MIND day centre members, like other respondents, placed more emphasis on intrinsic benefits, and mentioned these more frequently than extrinsic rewards.

57. Some participants were paid small sums for particular tasks: e.g. stewards in Eastvale MIND's day centre.

59. In answer to schedule 9, Question 4b (ii) Appendix 1.9).

60. In addition to the intrinsic benefits and problems outlined in Tables 8.4 and 8.5, two respondents mentioned, as benefits, development or use of skills and abilities, and gaining knowledge and increased horizons. Four respondents, mentioned as problems, insufficient opportunity to give or receive help or friendship.

61. HUGHES, A. 1985, op cit, p. 87.


65. See Table 8.4, p 246 A


71. HUGHES, A. 1985, op cit, p 79.


This is described further in Chapter 9.


This is further considered in Chapters 9 and 10.

See Chapter 7.

This is further described in Chapters 5 and 12.

See Chapter 12, p 337.

Described in Chapter 7, p 188.

These factors are considered in detail in Chapter 9.

The difference in complexity of Executive Committee meetings of Eastvale MIND and Westhill MIND is described in Chapter 7, p 176.

Issues related to communication and the structure of meetings as facilitating or hindering consumer involvement are further considered in Chapter 12.

I.E., the Trade Union to which some National MIND staff members belonged.
89. Interview. National MIND staff member.

90. Only one of these respondents actually used the word "exploited".

91. This respondent's views on this point are quoted on p245 of this chapter.

92. This is examined in Chapter 10.

93. See Chapter 3, p 72f for an account of distinctions between "real participation" and "pseudoparticipation" in the literature.


97. See References listed under Note 13.


105. This is further described in Chapter 10, p 276 f.


108. Since the period of fieldwork (August, 1985, to October 1985) the Patient's Rights Movement has grown considerably, with several groups which are members of the Umbrella Organisation "Survivors Speak Out".

109. This lack of awareness could be described as false consciousness. (BERGER, P.L. and LUCKMANN, T. 1967, op cit). CHAMBERLIN, J. 1988, op cit, describes false consciousness in users of mental health services.


111. See Chapter 3, p 72 f.


113. See Chapter 5, .
CHAPTER 9 - NOTES


10. NATIONAL COUNCIL FOR VOLUNTARY ORGANISATION 1984, op cit, p 60.


20. Respondents were asked to comment on this in relation to the level of the organisation with which they were most involved (National, Regional or Local). Besides those indicated in Table 9,1 benefits to the organisation or to other participants, which were mentioned, each by less than six respondents, were as follows: Positive effects on democracy (four); better decision making (three); benefits to the organisation from consumer involvement in responsibility and decision making (two); benefits to the organisation from individuals’ psychological gains (one); ulterior gains (one). (Numbers refer to the number of respondents reporting each benefit).

Problems to the organisation, or to other participants, which were mentioned, each by less than six respondents, were as follows: consumer’ lack of skills and abilities (four); adverse effects on the organisation because of consumers’ limited power or choice (four); wrong decisions being made (three); adverse effects on the organisation because of the lack of salience of participation to consumers (two); problems of confidentiality (one), and of accountability (one); lack of change resulting from consumer involvement (one); (Numbers refer to the number of respondents reporting each problem.)

21. Also known as self help. (RICHARDSON, A. and GOODMAN, M. 1983, op cit, p 1.).

22. KATZ AND BENDER define Self Help Groups as:

"..voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change.. Self Help Groups emphasise face-to-face social interactions and the assumption of personal responsibility of members...".


27. This is further considered in Chapter 10, p 319 ff.


32. This is considered later in this Chapter, p 293 .

33. This is discussed further in Chapter 11.


36. FOWLER, P.R. 1987a, op cit, p 32.

37. FOWLER, P.R. 1987a, op cit.


39. This issue is discussed in Chapter 11, p 293f

40. FOWLER, P.R. 1987a, op cit, p 32.


52. Participants' attitudes, as a factor facilitating or hindering consumer involvement, is considered in Chapters 10, 11 and 14.

53. This is further described in Chapter 7 (in relation to Westhill MIND) and Chapter 11.


55. This is described in Chapter 8, p260f.

56. However, it was difficult to assess the extent of the contribution of consumers in Local Associations with high consumer involvement because of the small numbers interviewed. Respondents' views may not have been representative of other participants in their Local Association.
57. See Chapter 7.

58. Interview. Officer, Executive Committee, Eastvale MIND.

59. Interview. Day Centre Member, Eastvale MIND.

60. Interview. Staff Member, National MIND.

61. This is described in Chapter 7.

62. This respondent was interviewed a few months after the main period of fieldwork in Westhill MIND, by which time there was more consumer involvement in campaigning.


65. Ways in which the structure of meetings may facilitate or hinder consumer involvement are discussed in Chapter 12.

66. This is further discussed in Chapter 10.

67. Interview. Officer, Executive Committee, Eastvale MIND.

68. Interview. Officer, Executive Committee, Eastvale MIND. See Chapter 7, p 189ff for a further discussion of accountability in the Local Association.

69. This is further considered in Chapter 12.

70. Chapter 10 considers the extent to which other participants’ beliefs about consumers affected their involvement.

71. The term "sufferer" was used in both the National Schizophrenia Fellowship and the Manic Depression Fellowship to describe people who had schizophrenia or manic-depressive psychosis, respectively.

72. See Chapter 8, p 279.

73. Chapter 10 includes an account of ways in which members of the Manic Depression Fellowship, and other respondents, attempted to resolve such problems, and considers ways in which individuals’ mental health problems facilitated and hindered Consumer Involvement.


78. WARREN, R.C. 1976, op cit.


84. HUNT P. and REYNOLDS, M.A. 1985, op cit.


89. WOODIN, J. 1985, op cit, p 1365.


92. The variety of needs and interests served have been outlined in Chapters 4 and 6 (in relation to National and Regional MIND) and 7 (in relation to Eastvale MIND and Westhill MIND). The serving of different interests in MIND is also considered in Chapter 13.
93. Source: Responses to schedule 1, Question 31 and Schedule 2, Question 6b (Appendices 1.1 and 1.2).

94. See Chapter 7, p 221f.

95. Schedule 1, Question 32a and 32b (Appendix 1.1).

96. Of thirteen respondents asked this question six people felt there was a conflict between consumer and professional interests, three felt that they complemented each other, one did not know, and two gave other replies. The number of respondents asked this question is too small for conclusions to be drawn about the views of National MIND participants.

97. There is an unclear word here in the interview transcript.

98. Interview. Professional member, Council of Management.

99. These activities were run by Training and Education Department staff. See Chapter 6.

100. See Chapter 7 for a further account of this.


102. See Chapter 7.

103. Interview. Lay Executive Committee Member, Eastvale MIND.


105. Source: Participant observation notes.

106. See Chapter 8, p 295f.

107. See this Chapter, p 282f.


114. See Chapter 6 for a discussion of these points.

115. This is discussed more fully in Chapter 6.

116. This is discussed in Chapter 12.
CHAPTER 10 — NOTES

1. The selection, for study, of Local Associations with high consumer involvement is described in Chapter 8, p 231.

2. A mistake was made in the wording of the question on this topic (Schedule 1, Question 30 Appendix 1.1). "Mitigate" should have read "militate against". Respondents were asked this question in relation to the level of the organisation in which they were mainly involved.

3. In addition to the factors mentioned in Table 10.1, two Westhill MIND respondents referred to the organisation/representation of consumers as a hindering factor.

4. Factors included under "other", each mentioned by one to three respondents, included "middle class people" (mentioned by three Local Association participants as a hindering factor); officers of the Executive Committee; and "non-consumer" participants (unspecified).


27. CARO, F.G. 1981, op cit, p 79.


34. PIVEN, F.F. 1968, op cit, p 117.


36. CHELL, E. 1986, op cit, p 42f.


39. See Chapter 7, p. 194f.

40. This is described more fully in Chapters 7 and 8.

41. Soon after the end of the main period of fieldwork in Westhill MIND, consumer involvement in this Local Association increased considerably, with several consumers being elected to the Executive Committee, and the formation of a group, consisting mainly of consumers, who facilitated Patient Participation in local psychiatric hospitals and units. This is briefly described at the end of Chapter 7 (p195f).

42. See Chapter 9, p 255f.

43. RICHARDSON, A. 1983, op cit, p 102f.


52. MARRIS, P. and REIN M. 1968, op cit.

53. ALINSKY, S. 1968, op cit, p 150.


61. See Chapter 7, p 170f.

62. A weakness of the study is that respondents were not asked who had initiated consumer involvement in their Local Associations, but several people indicated this in reply to other questions.

63. See Chapter 9, p 285f.

64. Source: Interviews with participants in Local Associations with high consumer involvement.
65. Source: Interviews and participant observation notes.

66. See Chapter 7.

67. Source: Interview, Westhill MIND club member.

68. These and other aspects of participation, are described in more detail in Chapter 7.


73. CHAMBERLIN, J. 1988, op cit.


76. PATEMAN, C. 1970, p 51 f.

77. CHAMBERLIN, J. 1978, op cit.

78. DYER, L. and McAUSLAND, T. 1985, op cit, p 2.


80. This is further described in Chapter 6, p 253 f.

81. See Chapter 9, especially p 285 f.

82. Respondents who mentioned skills which facilitated consumer involvement included some who described specific skills of particular consumers within MIND, and others who referred to skills which, they felt, consumers should have ideally.
This is considered later in chapter 12.

See Table 8.1, p 232.


See Chapter 9, p 294 f.

See Chapter 14, p 319 f.

Ways in which some respondents overcame this problem are described in Chapter 9, p 2.


This is further described in Chapter 9, p 287 f.

RICHARDSON, A. 1983, op cit, p 17. (See Chapter 8, p 236 f.


98. See Chapter 6, p 152f.


100. Source: telephone conversation and interview with respondent.


111. Ibid.


118. See Chapter 6 p .

119. See Chapter 7 p .

120. MIND, Undated, b. How to Set up a MIND Local Association. (Internal document).


122. Source: interviews with MIND participants.

123. See Chapter 10 p 319 f

124. See Chapter 10 p 319 f

125. See Chapter 9, p 281 f.

126. This is outlined in Chapter 11.


130. BROWN, P. 1985a, op cit, p 132.

131. BELLIN, A. 1981, op cit, p 86.

132. This is further described in Chapter 12 p 383.

133. This is further described in Chapter 6 p 133f.

134. Source: interview with this respondent.

135. This is further described in Chapter 7,

136. Source: interviews with members of Eastvale MIND and participant observation notes.

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137. I.e., "loons" or lunatics (Rhyming slang).


140. Ibid, p 2.


142. NATIONAL SCHIZOPHRENIA FELLOWSHIP, 1985c, op cit.


144. Ibid.

145. Respondents used the term "sufferer" to refer to members who had had endogenous depression or hypomania.

146. Source: Interview with committee members of local branch of the Manic Depression Fellowship.

147. Source: Interview with committee member of local branch of the Manic Depression Fellowship.

148. Source: National Schizophrenia Fellowship literature and interviews with members of the National schizophrenia Fellowship and Manic Depression Fellowship.
CHAPTER 11 - NOTES


23. See Chapter 8.

24. RICHARDSON, A. 1983, p 64.


40. MILLER, P. 1986, op cit.


51. DEPARTMENT OF HEALTH. Caring for People. Community Care in the Next Decade and Beyond. Cm 849. London. H.M.S.O.


68. CHAMBERLIN, J. 1988, op cit.


71. CAMPBELL, P. 1990, op cit, p 74.

72. CAMPBELL, P. 1990, op cit, p 74.

73. CAMPBELL, P. 1990, op cit, p 74f.

74. FOWLER, P.R. 1987a, op cit, p 76.

75. Interview with staff member of Eastvale MIND.

76. This is described in Chapter 7, p 176f

77. See Chapter 7, p 195.

78. See Chapter 14, p 546f.

79. See Chapter 9, p 276f.


82. See Chapter 10 above.


93. MILNER, N. 1981, op cit, p 38.


96. MILNER, N. 1981, op cit, p 40.

97. RAMON, S. 1985, op cit, p 175, referring to MAYER-GROSS SLATER and ROTH, Clinical Psychiatry.


100. CAMPBELL, P. 1989a, op cit, p 12f.


104. See Chapter 1C.


110. GRAYCAR, A. 1977, op cit, p 245.

111. Typologies of participation are discussed in Chapter 3 and 15. See also p362f this chapter where it is concluded, from evidence from this study, and from the literature, that participation is a complex phenomenon involving various amounts of power.


However, the idea of "false consciousness" has been criticised on philosophical and sociological grounds (POPPER, K. 1963). Conjectures and Refutations. The Growth of Scientific Knowledge, London. Routledge and Kegan Paul).


116. These factors are considered in Chapter 9, p 27\text{-}f.

117. This is considered in Chapter 12, p 37\text{-}f.

118. JAQUES, E. 1976, op cit.

119. It would have added considerably to the study to have asked all National MIND respondents to rate consumers' overall influence on decision making, compared with that of other groups. Unfortunately, this did not occur to me until quite late during the period of fieldwork at National MIND.
120. This is described in more detail in Chapter 6, p. 59 ff.

121. Mention has previously been made of benefits and problems related to perceived increases/decreases in consumer power. See Chapter 8, p. 263 ff.

122. This is described in Chapter 8, p. 263 ff.

123. These are outlined in Chapter 6, p. 263 and are further described in Chapter 12, p.

124. Such changes are considered in Chapter 6, p. 263 and Chapter 12, p.
CHAPTER 12 - NOTES


2. Source: literature listed above, and interviews with respondents in these organisations.

3. This is further described in Chapter 5.

4. Source: literature of these organisations and interviews with respondents.


8. See Chapter 7, p 221 f.

9. Source: interview with National Director MIND.


12. Organisations which merged to become the National Association for Mental Health in November, 1946, included: the Central Association for Mental Welfare, the National Council for Mental Hygiene and the Child Guidance Council. These are further described in Chapter 4, p 87 f.

14. DEPRESSIVES ANONYMOUS Undated, op cit.

15. MANIC DEPRESSION FELLOWSHIP, Undated. Circular letter to new enquirers.


17. All of the other voluntary organisations studied were keen to develop links with interested professionals.


23. CAMPAIGN AGAINST PSYCHIATRIC OPPRESSION. Undated, op cit.


29. See Chapters 5 to 7.


36. RILEY, W. 1981, op cit, p 44.


40. SMITH, L. 1981b, op cit, p 52.


42. This is further described in Chapter 6 and 13.

43. See Chapter 6, p 140f.

44. Schedule 1, Q28b (Appendix 1.1).

45. The following items were each mentioned by two respondents: consumer representation at different levels of MIND; MIND's advocacy and information services; involvement in publications; participation in workshops and conferences; work as a volunteer; decreasing the involvement of mental health professionals in MIND; representation on the new regional councils.

46. See Chapter 6, p 140f and Chapter 8, p 240f.

47. Schedule 2, Q.4. (Appendix 1.2).

48. Fourteen National MIND staff members and nine volunteers were asked this question.

49. Source: Interview, National MIND volunteer.

50. Source: Interview, Council of Management member.

51. Source: Interview, National MIND volunteer.

52. Source: Interview, mental health professional member of Council of Management.
53. An explanation of Forum is given in Chapter 1, p 10.
54. Source: Interview, National MIND staff member.
55. This is further described in Chapter 6, p 157f.
56. This is further described in Chapter 6, p 133.
57. Interview, National MIND staff member.
58. Interview, National MIND staff member.
63. CHAMBERLIN, J. 1988, op cit p 211f.


69. See Chapter 42, p 404 f.

70. See Chapter 14, p 462 f.


76. MARRIS, P. and REIN, M. 1968, op cit, p 131.
78. JAQUES, E. 1976, op cit, p 206f.
80. SMITH, J. 1987, op cit, p 83.
82. FOWLER, P.R. 1987a, op cit, p 72.
83. COLOM, E. 1981, op cit, p 95.
85. CARO, F.G. 1981, op cit, p 79.
86. SMITH, L. 1981a, op cit, p 17.
90. CHAMBERLIN, J. 1988, op cit.


96. See Chapter 7, p 177 ff.

97. As the fieldwork progressed, interviews became less structured, and the interviewer sometimes made comments. The problems and advantages of this are discussed in Chapter 2.

98. Source: interviews with Westhill MIND Club Members.


100. Source: interviews with participants in Local Associations with High Consumer Involvement.

101. This is considered in Chapter 7, p 207 ff.

102. Source: Interviews with National MIND participants.

103. Source: Interview. Staff member, National MIND.

104. Source: Interviews, Local Association participants.

105. Source: Interviews with members of Westill MIND.

106. This is further considered in Chapter 7, p 176.

107. Source: Participation observation notes. The complexity of meetings is considered in Chapter 7, p 178 and later in this chapter, p 398 ff.


111. This is described in Chapter 7, p 196; Chapter 9, and Chapter 11, p 354-6.

112. This is further discussed in Chapter 11, p 354.

113. Interview. Chairperson, Local Association with high consumer involvement.


118. See Chapter 7, op cit, and Chapter 8, p 259.

119. Source: Interviews with respondents in Local Associations with high consumer involvement.

120. Source: Interviews with respondents in Local Associations with high consumer involvement.

121. This is further described in Chapter 6, p 150 f.

122. Interviews, Assistant Director, National MIND.

123. Source: Interview, Staff Member, National MIND.

124. Source: Interview, lay officer of Executive Committee, Westhill MIND.

125. This is described in Chapter 7, p 194.

126. See Chapter 7, p 196 f.

127. This proved to be the case, according to a staff member who was interviewed about three months after the period of fieldwork in Westhill MIND.

128. Interview, Chairperson of fund raising sub committee and consumer Executive Committee member, Eastvale MIND.

129. Source: Interviews, Training Officers, National MIND.

130. Source: Interview, Council of Management member.


133. See Chapter 10, p .
134. Interview, Regional Director.

135. Interview, Volunteer, National MIND.

136. Source: participant observation notes.

137. Interview, Regional Director.

138. Source: interviews with National MIND participant.
1. See Chapters 10 to 12.


14. HANDEY, C.B. 1981, op cit, p121. Whether this power is "negative" or not depends on the perspectives of the superordinate and subordinate, a point not made by Handy.


17. RHODES, R.A.W. 1988, op cit, pp 165 f and 405f.

18. Ibid, p165f.


25. RHODES, R.A.W. 1988, op cit, pp 61, 165f and 403,


28. See Chapter 4, p 90f.
29. Secretarial and ancillary staff were accountable to the General Secretary.

30. Both the Management Team and the policy committee were chaired by the National Director. Other members of the Management Team were the General Secretary, all Assistant Directors of National departments and all Regional Directors. The Policy Committee included five council of management members, five Management Team members and five staff representatives who might be of senior or junior level.

31. HEGINBOTHAM, C. Undated (probably written in 1983). Decision Making and Accountability within MIND. A Consultative Document (internal MIND document). Local Associations were also represented on Regional Advisory Councils, where they advised, but did not manage regional offices.

32. HEGINBOTHAM, C. Undated, op cit.


35. Ibid, p 300.

36. Source: interview, Assistant Director.

37. Source: interview, Council of Management member.

38. Source: interviews with various respondents.

39. Source: written records in Community Department, National MIND.

40. JAQUES, E. 1976, op cit.


43. RHODES, R.A.W. 1988, op cit. My thanks to Gerald Wistow for pointing this out.

44. Sources: records on Local Associations in the Community Development Department, National MIND, and interviews with Regional MIND staff.

45. However, the Secretary was later accepting of the research, once further explanations were given.

46. Source: interview, Secretary, Westhill MIND.

47. Source: interviews, Westhill MIND participants.
48. Source: interviews with Eastvale MIND Executive Committee officers and members.


51. Ibid, p110.

52. This was the Queen Adelaide Fund, which was administered by National MIND's Community Development Department during the period of fieldwork.


55. Source: interviews and participant observation.


59. Ibid.

60. Ibid.


63. MIND 1985a, op cit, p13f.

64. See Chapter 6, p. 1114f


66. See Chapter 12, p. 3 80 f.

67. This is described further in Chapter 6, p 152 f.

68. Source: participant observation notes.


71. See Chapter 14, p 449 f.


73. ETZIONI, A. 1964, op cit.


75. Ibid, p 206.

76. Ibid, p 204 f.

77. Ibid, p 274 f.

78. JAQUES, E. 1976, op cit.

79. Ie, National or Regional MIND, or in the case of Eastvale and Westhill MIND members, their Local Association.

80. The following Table (next page) indicates respondents' views on the main aims of National and Regional MIND, and of Eastvale and Westhill MIND. (Each respondent was asked about the aims of the level of MIND in which (s)he was principally involved). Many respondents mentioned more than one aim.
<table>
<thead>
<tr>
<th>Perceived Main Aim</th>
<th>National</th>
<th>Regional</th>
<th>Eastvale</th>
<th>Westhill</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=29</td>
<td>n=11</td>
<td>n=12</td>
<td>n=10</td>
</tr>
<tr>
<td>Service provision</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Influencing statutory mental health services (in general)</td>
<td>9</td>
<td>5</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Influencing development of community mental health services</td>
<td>8</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Public Education</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Campaigning</td>
<td>9</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Attempts to influence central and/or local government</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Information and advice</td>
<td>2</td>
<td>4</td>
<td>0</td>
<td>1</td>
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<tr>
<td>Legal issues</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Rights related to welfare/discrimination</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Consumer involvement (stated as an aim)</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Education of professionals</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Tranquillisers campaign</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Work with Local Associations</td>
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<td>4</td>
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</table>
81. Schedule 1, Q 114. Only 19 respondents were asked this question, of whom one gave an unequivocal "Yes", ten said "No", and seven that it depended on the Local Association. See Chapter 2 for an explanation why a limited number of respondents were asked this and other questions.

82. See Chapter 13, p.

83. Source: interviews with Eastvale and Westhill MIND Local Association participants.

84. Source: analysis of results of questionnaire by a Regional Development Officer and interview with this respondent to whom I am very grateful for access to this information.

85. See Chapter 13, p.

86. Other factors contributing to the limited impact of National and Regional MIND in this respect are considered elsewhere in this Chapter (p ).

87. CHELL, E. 1986, op cit, p 97.

88. Schedule 1 Q20.

89. National MIND Staff Members' estimates of communication with Local Associations were as follows: n = 15

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<tr>
<td>Nil</td>
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90. Topics of communication from National MIND staff to Local Association participants were said to be as follows: (Some respondents mentioned more than one item). n15

- Providing information or help: 8
- Training matters: 6
- Referral of clients to Local Associations: 5
- Asking Local Associations for information or opinions: 3
- Local mental health issues: 2
- Asking for support with campaigns: 2
- Matters concerning consumer involvement: 2
- Visiting or speaking at Local Association meetings: 2
- Attending forum meetings: 2
- Local Association membership: 1

91. Source: interviews with Local Associations Co-ordinator and a member of Forum.

93. During the time of field work, four of the six MIND Regions had a Regional Development Officer, and two of these Regions also had one other statutory-funded Development Officer to develop Local Associations in part of the Region. The Community Development Office Headquarters also had a Development Officer, who became the Regional Development Officer for South East MIND towards the end of the period of fieldwork.

94. This point is examined later in this Chapter (p 43).

95. Source: interview with Regional Development Officers.

96. Source: interview with a Regional Director.

97. Issues related to consumer involvement, statutory policies and advice, information and help with Local Association problems were each mentioned by three out of seven regions; and campaigning/advocacy, educational issues and "getting Local Associations to examine what they do", were each mentioned by two regions.

98. See Questionnaire 1, (Appendix 2.)

99. One of these respondents rated communication on consumer involvement as "nil".

100. Source: interview, staff member, Westhill MIND.

101. At the time of fieldwork, established regions included North West, Northern, Trent and Yorkshire, Wales and West Midlands MIND. South West MIND had not long been established, and South East MIND, (which developed from the Community Development Department in the National Office) was established in late 1985, just after the period of fieldwork.

102. See Chapter 6, p 98 for an explanation of Regional Councils.

103. See Chapter 6, p 142 and Chapter 14, p 145 for brief accounts of Region C staff's projects to facilitate consumer involvement.

104. Executive Committee members' contact with National and Regional MIND was as follows:
### CONTACT WITH NATIONAL MIND

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### CONTACT WITH REGIONAL MIND

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<td>5</td>
</tr>
<tr>
<td>Not asked</td>
<td>2</td>
<td>1</td>
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</tbody>
</table>

105. Source: interviews with Eastvale and Westhill MIND Executive Committee members.

106. Source: interviews with Eastvale and Westhill MIND Executive Committee members.

107. Source: interview, Chairperson, Westhill MIND. This Local Association has its origins in a Local Association of the Central Association for Mental welfare, one of the organisations which merged to become N.A.M.H. (see Chapter 4, p. and Chapter 7, p. 640).
CHAPTER 14 - NOTES

1. Most respondents quantified the amount of influence of National MIND on Local Associations with answers such as "quite a lot" or "very little". The categories in Table 14.1 are based on retrospective analysis of responses. In retrospect, it would have been better to have invited respondents to choose scaled responses from a Likert rating scale, as was the case with some other questions (eg. Schedule 1, Qs 33 and 35 to 38 (Appendix 1.1)).

2. Source: interviews.


4. See Chapter 13, p 42.5 F.


6. This is referred to in Chapter 13.

7. Source: interviews, MIND respondents. These points are considered elsewhere in this Chapter.

8. See Chapter 6, p 144 F.

9. Schedule 1, Q. 1.16b.

10. Source: interviews with National MIND respondents.

11. Source: interviews, Regional Directors.

12. A weakness of the study is that more staff than Council of Management and Forum participants were interviewed.

13. See Chapter 6, p 138 F.

14. See Chapter 6, p 143 F.

15. Source: interviews with staff members of the Black and Minority Ethnic Team.


17. Source: interviews with Local Associations Co-ordinator and other respondents.

18. Source: interviews with National and Regional MIND respondents.
19. Source: notes based on non-participant observation at an open meeting of National MIND.


21. See Chapter 13, p. 4.36

22. Source: interview with Regional Director.

23. Source: interview with Secretary, Southbury MIND.

24. Source: interviews with Regional Directors.

25. See Chapter 6, p. 4.2.

26. Source: interviews with members of Local Associations with high consumer involvement in Region C.

27. Source: interview, with Regional Development Officer.

28. Source: interview, Regional Development Officer.

29. Source: interview, Regional Director.

30. Source: interviews, Regional Development Officer.

31. Source: interviews with respondents in Local Associations with high consumer involvement.

32. Not all National and Regional MIND respondents were asked this question (Schedule 1, Q. 19 (1) a): a fault of the study. Estimations of Local Associations' influence are based on retrospective analysis. In this and other questions, it would have added to the study to have asked respondents to assess Local Associations' influence on a rating scale.

33. Source: interview, National Director.

34. Schedule 1, Q19 (i) a (Appendix 1.1) on this topic was dropped after the first few interviews to reduce the length of the interview schedule.

35. This is considered in Chapter 13, p. 4.32f.

36. Source: interview, Assistant Director, National MIND.

37. Source: interview, staff member, National MIND.
38. This was one of the highest incidences of "don't knows" in the study.

39. Schedule 1, Q, 19 (i) (Appendix 1.1). Only eight respondents were asked this question, of whom six said "nil".

40. Source: interview, chairperson of Eastvale MIND.

41. Source: interviews with two officers, Westhill MIND.

42. Source: interview, secretary of Westhill MIND.

43. Source: interviews with Local Association respondents.

44. Schedule 9, Q12, and schedule 11, Qs 10c and 11. (Appendix 1.9 and 1.11). Weaknesses of the study are that a limited number of Eastvale MIND day centre members were asked about this, and that the question was phrased in a leading way. A few day centre members misunderstood the question and thought that it referred to Eastvale MIND.

45. Ten out of fifteen day centre members, and three out of six club members were asked a question on this topic (schedule 10, Q24 Appendix 1.10).

46. Source: interviews with respondents with consumer experience in Local Associations with high consumer involvement. (schedule 11, Q10c (i), Appendix 1.11).

47. Source: interviews with consumer participants in Local Associations with high consumer involvement.

48. Ratings are based on retrospective analysis.

49. Source: interviews with MIND respondents.

50. For this reason, data from interview responses may over-emphasise the influence of National and Regional MIND on the development of consumer involvement.

51. Source: interview, Westhill MIND staff member.

52. Source: interview with respondent in Local Association with high consumer involvement.

53. Source: interviews with Regional MIND staff.

54. Source: interview with Regional Development Officer.

55. Source: interview with Council of Management member.

56. Source: interview with Regional MIND staff member.

57. Source: interviews with MIND respondents.

58. Source: interview with National MIND staff member.
59. Source: interview with professional member of Council of Management.
1. See Chapter 3, p S4F.


4. Source: interview with Westhill MIND staff member.


14. This is discussed further in Chapter 3, p 53.


17. This is considered in Chapter 2.

19. This is discussed in Chapter 2.


21. See Chapter 6, p 12 f.

22. This is further discussed in Chapter 3, p 53.


25. See Chapter 6, p.


28. These points are discussed in Chapter 6 and 12.

29. The extent of consumer involvement in National and Regional MIND is further described in Chapter 6.

30. Further details of consumer involvement in Eastvale and Westhill MIND are given in Chapter 7.

31. See Chapter 7 and 14 (pp 220 f and 462 f, respectively).

32. See Chapter 12, p 370 f.

33. All these aspects of consumer involvement are described in Chapters 6 to 9.

34. See Chapters 7 and 10.

36. See Chapter 6, p 133 f.

37. Source: interviews with senior civil servants in the (then) D.H.S.S. and with three politicians with involvement in MIND.


40. See Chapter 3, p 66 f.


42. See Chapter 3, p 67.


44. See chapter 14, p 462 f. Richardson questions whether power is necessarily a component of participation. (RICHARDSON, A. 1983, op cit, p 79 f.)

45. See Chapter 3, p 67 and Chapter 11, p 317 f.

46. See Chapter 7 and 10.


48. See Chapter 13, p 429 f.


52. See Chapter 3, p 78.

53. See Chapter 6, p 120 f.

54. See Chapter 6, p 135 f.

55. Source: interview with this respondent.

56. See Chapter 10, p 337.


58. See Chapter 9, p 241 f.

59. See Chapter 8, p 240 f.

60. These points are further discussed in Chapter 7.

61. See Chapter 7, p 188.

62. See Chapter 7, p 181 f.

63. This is considered further in Chapter 16.

64. See Chapter 8, p 241.

65. See Chapter 8, p 231 f.

66. See Chapter 9.


69. See Chapter 10, p 309 f.


71. See Chapter 10, p 319 f.

72. See Chapter 12, p 383 f.


74. See Chapter 6, p 336 f and chapter 10, p 336 f.

75. CHAMBERLIN, J. 1988, op cit, p 71.

76. See Chapter 9, p 274 f and chapter 10, p 319 f.

77. See Chapter 10, p 338 f.


80. See Chapter 16, p 528.

81. See Chapter 10, p 341 f.

82. This is further described in Chapter 11, p 347 f.

83. See Chapter 7, p 196 f.

84. These are described in Chapter 11, p 362 f.

85. See Chapter 11, p 364 f.

86. See Chapter 6, p 265 f.

87. See Chapter 12, p 372 f.

88. These proposals are discussed in Chapters 6 and 12.

89. See Chapter 12, p 394 f.
90. See Chapter 12, p. 396 ff.

91. See Chapter 7, p. 194 and Chapter 12, p. 402 ff.

92. See Chapter 12, p. 404 ff.


94. See Chapter 14, p. 445 ff.

95. This is described further in Chapter 14, p. 448 ff.

96. See Chapter 14, p. 465 ff.
NOTES – CHAPTER 16


2. See Chapter 14, p 453f.


4. See Chapter 5, pp 109 and 116f for a consideration of the typologies of Gerard and Band, based on Brager et al.


8. This is further considered in Chapter 8, p 236f and Chapter 10, p 213f.


10. See Chapter 7.


13. These aspects of participation are considered in more detail in Chapter 15, and are illustrated in Fig. 15.1.


15. JONES, M. 1968, op cit.


18. See Chapter 9, p. 297f.


22. This is discussed in Chapter 12.


28. This is further discussed in Chapter 11.

29. See Chapter 7.


33. See Chapter 13.

34. See Chapter 14.

35. Both the chairperson of Council of Management, and the National Director expressed commitment to increasing consumer involvement. (See Chapter 5 and 6).
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MIND. Undated a. How to set up a MIND Local Association, (Leaflet).


(NATIONAL ASSOCIATION FOR MENTAL HEALTH. LITERATURE AFTER 1971 IS LISTED UNDER MIND).


APPENDICES
The order of questions has been changed from that of the original version of this schedule, in order to ensure greater clarity. Other questions were included, but these were subsequently dropped because the number of questions was found to be excessive.

In addition, some other questions have not been included in this revised version because they were on topics which have not been considered in this thesis.

1. What do you see as the most important aspects of: a) your role as —; b) the work of the — Department?

2. a) What do you see as the most important aims of National MIND?

   b) In what ways do MIND's main aims differ from those of five years ago?

   QUESTIONS ON CONSUMER INVOLVEMENT

3. In your view, which people are the "consumers" in relation to mental health services?

4. The term "consumer involvement" has recently been used a lot by some people in National MIND.
   a) What is your understanding of the meaning of this term?
   b) Why should there be consumer involvement in MIND?

5. How committed would you say:
   a) National MIND generally;
   b) The Council of Management, are to increasing consumer involvement?

6. How important is the facilitation of consumer involvement compared with other aims of National MIND?
7. How much importance is attached to consumer involvement in
National MIND, compared with five years ago?

8. Does MIND at National or Regional levels have any clearly
defined objectives in relation to consumer involvement?

9. In what ways, if any, is consumer involvement actively
promoted or encouraged by:
   a) National MIND.
   b) (OR REGIONAL STAFF) - Regional MIND?

10. In a) - Department/Region; b) National MIND as a whole, to
what extent do consumer views influence decision making
about their needs and rights in the following ways:
   1. Staff consider consumers' expressed views and
      needs - e.g. from letters, phone calls;
   2. Staff assess consumer views and opinions
      informally/formally (e.g. through research
      undertaken by MIND);
   3. Consumers are actively involved in decision
      making?

11. Overall, in your view, to what extent do a) Local
    Associations; b) Regions:
    a) Have similar aims to National MIND?
    b) Should have similar aims to National MIND?

12. To what extent do you think: a) Local Associations, b) Regions,
    agree or disagree with National MIND policies?

13. Are there any particular issues with which (i) Regions,
    (ii) Local Associations, particularly agree or disagree
    with National MIND?

14. What do you see as the main advantages and disadvantages of
    Local Associations:
    a) Collaborating closely with local statutory
       services?
    b) Receiving large amounts of funding from a Social
       Services Department or District Health Authority?

15. To what extent do you think Forum effectively represents
    the views of (i) Local Associations; ii) consumers who use
    MIND services?
16. To what extent do you think the proposed changes in management structure, responsibility and accountability will:

a) increase the influence of Local Associations on National MIND policy;

b) increase the influence of National MIND on Local Associations;

c) increase the amount of consumer involvement in MIND?

17. To what extent do you think National MIND influences:

(i) Local Association policies;

(ii) Regional MIND policies?

18. To what extent do you think Local Associations are autonomous in the sense of deciding their own aims and priorities?

19. Overall, how much influence do you think:

(i) Local Associations. (ii) Regional participants have on:

a) National MIND policies;

b) The policies and work of the - Department?

20. How much communication is there between the - Department and Local Associations?

20b. On what sorts of issues does the - Department communicate most frequently with Local Associations?

20c. Which members of Local Associations do you and other members of the - Department most frequently communicate with?

(CHECKLIST

CONSUMERS, LAY PEOPLE
MENTAL HEALTH PROFESSIONALS, STAFF MEMBERS).

21a. How frequently do Local Associations communicate directly with the - Department?

21b. On what sorts of issues do Local Associations most frequently communicate with the - Department?
21c. Which members of Local Associations communicate most frequently with the - Department?

(CHECKLIST:

CONSUMERS
LAY PEOPLE
MENTAL HEALTH PROFESSIONALS
STAFF MEMBERS)

22. In your view, which types of National Voluntary Organisation are most likely to receive Central Government funding at present?

a.) Voluntary organisations which concentrate on service provision, or on campaigning or a mixture of both.

b.) Voluntary organisations run by people with a professional background, or by consumers or a mixture of both.

c.) Voluntary organisations for children, the elderly, the physically handicapped, the mentally ill, the mentally handicapped.

23. To what extent do you think: a) consumers: a) lay people are involved in:

1. The Council of Management for National MIND;

2. Regional Advisory Councils?

24. To what extent do you think the following groups or people should be involved in:

a). The Council of Management;

b). Regional Advisory Councils?

1. Mental health professionals
2. Consumers
3. Lay people?
25. To what extent do you think the following groups of people are involved in:
   a. Forum.
   b. Local Association Executive Committees?
      (1) Mental health professionals;
      (2) Consumers;
      (3) Lay people?

26. To what extent do you think these groups of people should be involved in:
   a). Executive Committees;
   b). Local Associations?

27a. What do you see as the main role in National MIND of volunteers who have experienced mental health problems?

27b. Do you have any views on whether or not volunteers could expand their role in National MIND?

28a. What do you think of recent suggestions that there should be more consumer involvement in MIND?

28b. In what ways do you think consumer involvement in MIND can best be achieved?

28c. What do you think of the idea of a "Consumer Advisory Panel" to National MIND?

29. In what ways has consumer involvement in National MIND been:
   a) beneficial to the individual.
   b) caused problems to the individual.
   c) beneficial to the organisation.
   d) caused problems to the organisation.

30. Within MIND at a) National, b) local level, what factors, in your view:
   1. facilitate consumer involvement in decision making and taking on responsibility;
   2. militate against consumer involvement in decision making and taking on responsibility?

31. To what extent do you think it would be a) possible, b) desirable for consumers to run National MIND themselves?

32a. To what extent, if at all, do you think MIND serves professional interests?

32b. (IF APPROPRIATE) Does MIND's serving of professional interests complement or conflict with its representation of consumer interests?
33. In your view, to what extent does:

a) the Council of Management; b) senior MIND staff consult the views of consumers?

Nil Slight Fair Marked Considerable.

34. To what extent would it be appropriate for a) the Council of Management; b) senior MIND staff to do so?

35. Overall, to what extent are consumers involved in important decision making in National MIND?

Nil Slight Fair Marked Considerable.

36. Overall, how much are consumers involved in taking on responsibility in National MIND?

Nil Slight Fair Marked Considerable.

37. Overall, how much influence do you think consumers have on National MIND policy?

Nil Slight Fair Marked Considerable.

38. To what extent do you think self advocacy by consumers of their needs and rights: a) is encouraged by National MIND; b) should be encountered by National MIND?

INFLUENCING CENTRAL GOVERNMENT POLICY

39. To what extent do you think: a) the - Department, b) National MIND as a whole:

1. attempts to influence Central Government policies for mental health services;

2. actually influences Central Government policies for mental health services?

40. On what issues have a) the - Department, b) National MIND as a whole, attempted to influence central government policies?

41. To what extent, if at all, do you think consumer involvement in MIND should extend outside the organisation: e.g. in campaigning and other ways of attempting to influence Local and Central Government policies?
RESPONDENT’S OWN INVOLVEMENT

42. Can I ask why you originally became in the work of MIND?

43a. Do you represent MIND on any organisations or committees?

43b. (IF YES), To what extent do you feel you represent the views and felt needs of consumers?
APPENDIX 1.2

INTERVIEW SCHEDULE 2

COUNCIL OF MANAGEMENT OFFICERS AND MEMBERS

(In addition to questions in this schedule, Council of Management members were also asked some questions in Interview Schedule 1. (National MIND staff).

1. What are the most important aspects of:
   a) your work as a Council of Management member/officer;
   b) the work of the Council of Management?

2. How much influence do you think the following people have on policy making in National MIND?
   a) Consumers.
   b) Council of Management.
   c) Junior National MIND staff (i.e. below Assistant Director).
   d) Local Associations.
   e) Regional staff/regional advisory committee.
   f) Senior National MIND staff.

3. a) In your view, are there too many, about the right number, or too few of the following groups of people on the council of Management?
   i) mental health professionals;
   ii) people who see themselves as having experienced mental health problems;
   iii) other laypeople.
   b) What do you feel the composition of council of management should be?

4. Has Council of Management come to any decisions about how consumer involvement can best be achieved?

5. To what extent is there consumer involvement in Council of Management in the following ways?
   a) Members of Council of Management decide what they think is in consumers' best interests.
   b) Members base statements about consumer need on their experience of contact with consumers: e.g. through their work.
   c) Members recommend consultation of consumer views.
   d) Members recommend active involvement of consumers in decision making processes in MIND.
c) Some members of Council of Management have, or probably have, experience as consumers, themselves.

6. a) Why are about half the members of Council of Management mental health professionals?

b) Would it be possible, or feasible, for National MIND to be run completely by consumers?

7. a) To what extent is consumer involvement a topic for discussion in Council of Management meetings, compared with other issues?

b) To what extent does the move to increase consumer involvement in MIND come from council of management members?

c) Overall, how committed would you say: (i) Council of Management members; (ii) National MIND staff, are to increasing consumer involvement?

d) How important is increasing consumer involvement compared with other aims of National MIND?

8. There was recent discussion in Council of Management about whether members should state whether or not they had experienced mental health problems. To what extent do you think it would be a good idea or not for Council of Management members and senior national MIND staff to make it clear whether or not they have experienced mental health problems?

9. a) To your knowledge, have any consumers written to Council of Management on the topic of consumer involvement?

b) To what extent do you think the move to increase consumer involvement in National MIND has come from consumers themselves?

10. a) How satisfied are you with the way decisions are made:

i) within the Council of Management;

ii) in MIND as a whole?

b) Are there any changes which you would like to be made in the decision making process?

c) (IF YES TO 10b) what are they?

11. a) For what reasons did you become a member of the council of Management?

b) Are you on the Council of Management in your own right, or as a representative of - (ADD NAME OF ORGANISATION)?
12. To what extent do you feel that Council of Management is in touch with the views of:

a) people with mental health problems;
b) local associations;
c) regional staff/regional advisory committees;
d) junior national MIND staff;
e) senior national MIND staff?
APPENDIX 1.3

INTERVIEW SCHEDULE 3

NATIONAL MIND VOLUNTEERS

(Besides the questions in the schedule, National MIND volunteers were also asked many of the questions in Interview Schedule 1: National MIND staff).

1.

a) What do you see as the most important aspects of your work as a volunteer in National MIND?

b) Have you done other types of voluntary work with National MIND in the past?

c) How long have you been a volunteer in National MIND?

2.

a) Are you a member of a Local Association?

b) (IF YES TO 2a) which one?

c) Are you a member of National MIND?

3.

a) What do you like or dislike about your work as a volunteer in National MIND?

b) Do you think the role of volunteers could be expanded in National MIND or not?

c) (IF YES TO 3b) what other work do you think volunteers could do?

d) Are there any other things that you would like to do in MIND as a volunteer?

4.

a) Do you think volunteers get sufficient support or training from National MIND?

b) (IF NO TO 4a) What sort of support and/or training do you think should be provided by National MIND?
5. a) Do you think: (i) volunteers; (ii) other people with mental health problems have sufficient influence on decision making and taking on responsibility in National MIND?

b) (IF NO TO 5a). In what ways do you think.

   (i) volunteers;

   (ii) other people with experience of mental health problems could be more involved in decision making and responsibility in National MIND?

6. What was the reason for: a) (IF APPLICABLE) your originally joining MIND; b) your becoming a volunteer?

7. In what ways does the work of volunteers:

   a) result in benefits and problems to themselves;

   b) result in benefits and problems to National MIND?

8. To what extent, if at all, do you think distinctions are made between volunteers and other people in National MIND?

9. Have you been involved in MIND in other ways?

    Attending National MIND meetings/conferences.
    Involvement in other ways.

10. (IF YES TO 2a).

    a) Do you use the Local Association's facilities (e.g. centre or club)?

    b) In the Local Association, are you:

       i) a volunteer?

       ii) a member of officer of the Executive Committee?

       iii) a member of Forum, the Regional Advisory Committee or Council of Management?

    c) Do you take on any other responsibility in the Local Association?
d) Are you involved in decision making in any other way?

11. 

a) Would you like to take on more responsibility in National MIND as:
   i) a council of management member;
   ii) a staff member;
   iii) in other ways?

b) (IF YES TO 11a (iii). In what ways would you like to take on more responsibility?

12. In your view, what factors facilitate or mitigate against the involvement of volunteers in decision making and responsibility in National MIND?
APPENDIX 1.4

INTERVIEW SCHEDULE 4

MEMBERS OF LOCAL ASSOCIATIONS FORUM

(Members of Forum were also asked some of the questions in interview schedule 1: National MIND Staff).

1. a) What are the most important aspects of your work as a member/officer of Forum?
   b) Can I ask what your role is in - Local Association?

2. In your view, what are the main aims of Forum?

3. To what extent is:
   a) consumer involvement discussed in Forum;
   b) the concern of National MIND staff to increase consumer involvement influenced by Forum?

4. In what ways does Forum represent the felt needs and views of consumers?
   a) direct involvement of consumers in Forum;
   b) Forum members represent views expressed to them by consumers;
   c) Forum members decide what is in the best interests of consumers, without directly consulting them?

5. a) To what extent do you think: a) Forum; b) the Executive Committees of Local Associations are composed of:
   (i) mental health professionals;
   (ii) consumers;
   (iii) other lay people?
   b) Do you think there are not enough, enough or too many of each of these categories of people (i) in Forum; (ii) on Local Association Executive Committees?

6. How much consumer involvement is there in the Local Association you represent?
   a) No distinction between "consumers" and "non consumers"
   b) Consumers largely run the Local Association themselves.
   c) Consumers occupy officer/staff posts.
   d) Consumers are members of Executive Committee.
   e) Consumer involvement in political activity, such as campaigning, lobbying.
7. Can I ask the reasons why:
   a) you became involved in MIND;
   b) you became a Forum member?

8. How much influence do you think Forum has on Council of Management and its policies?
APPENDIX 1.5
INTERVIEW SCHEDULE 5
REGIONAL MIND STAFF

(In addition to the questions listed below, Regional MIND staff were asked many of the questions in interview schedule 1 (National MIND staff).

1. Overall, to what extent are the following groups of people members of Executive Committees in Region?
   a) mental health professionals;
   b) consumers;
   c) lay people

2. To what extent is there consumer participation in Regional MIND?
   a) volunteers;
   b) employment by Regional MIND of people with mental health problems.
   c) representation on Regional Council;
   d) encouragement of self advocacy;
   e) campaigning and other political activity.
   f) consumer involvement in decision making in Regional MIND?
   g) consumer involvement in other ways.

3. a) Were any Local Associations in Regional MIND started solely or partly by consumers?
   b) Do any Local Associations in the Region have:
      i) a high consumer involvement in Executive Committee membership.
      ii) considerable involvement in projects?

4. To what extent does Regional MIND:
   a) campaign for improvements in mental health services;
   b) collaborate with Health Authorities, Social Services Departments and statutory professionals?
5. a) How important is consumer involvement in the work of Regional MIND?

b) To what extent is Regional MIND concerned with:

i) Normalisation;
ii) Advocating consumers' rights and needs;
iii) Other work involving consumer involvement?

6. On what issues do you represent consumers' interests to policy makers at:

a) local level;
b) regional level;
c) central government level?
APPENDIX 1.6

INTERVIEW SCHEDULE 6

PRELIMINARY INTERVIEWS WITH RESPONDENTS INVOLVED IN LOCAL ASSOCIATIONS

These preliminary interviews were conducted with staff in "Albion" Region and with participants in Local Associations in an area of this Region.

The questions asked varied in each interview. The following schedule includes those most frequently used.

A. AIMS AND FUNCTIONS

1. What do you see as the most important aspects of your work/role as . — ?

2. What do you see as the most important aims of MIND/Associations for . — Mental Health?

3. In your view, what are the chief characteristics of a Local Association which is working successfully?

4. How important is each of the following functions or services in the work of the Local Association?

<table>
<thead>
<tr>
<th>FUNCTION OR SERVICE</th>
<th>DEGREE OF IMPORTANCE</th>
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<tbody>
<tr>
<td>Advice and information for consumers and their relatives on mental health and welfare issues.</td>
<td>NIL</td>
</tr>
<tr>
<td>Provision of other services for consumers or their relatives.</td>
<td></td>
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<tr>
<td>Fund raising activities</td>
<td></td>
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<tr>
<td>Education and information on mental health issues for general public or professionals</td>
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<tr>
<td>FUNCTION OR SERVICES</td>
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<tr>
<td></td>
<td>NIL</td>
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<tr>
<td>5. Publicity of the Local Association and of mental health issues</td>
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<tr>
<td>6. Campaigning for improvements in statutory mental health services</td>
<td></td>
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<tr>
<td>7. Legal Advocacy</td>
<td></td>
</tr>
<tr>
<td>8. Advocacy and representation of consumers' rights and needs, other than legal advocacy</td>
<td></td>
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<tr>
<td>9. Prevention of mental ill health</td>
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<tr>
<td>10. Other function(s)</td>
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5.

a) What do you see as the most positive features of the Local Association and its work?

b) What are the chief problems, if any, with which the Local Association is faced?

CHECKLIST

Problems related to:

- Difficulty in initiating projects.
- The running of projects.
- Obtaining fundings.
- Obtaining premises.
- Interest and support from statutory organisation and professionals.
- Executive committee members.
- Getting people to stand as Executive Committee Members/take positions of responsibility.

- Recruiting volunteers.
- Attracting consumers.
- Raising funds.
- Other Problems.
B THE EXECUTIVE COMMITTEE

6. Please can you tell me how many people on the Executive Committee are:
   a) mental health professionals or retired mental health professionals.
   b) people who, themselves, have personal experience of mental health problems.
   c) relatives of people with mental health problems.
   d) other lay people.

7. Do you think the Local Association has too many, too little, or about the right amount of these groups of people on its Executive Committee? (LIST AS FOR Q6).

8. In your view, what factors are essential to the effective working of an Executive Committee?

C. CONSUMER PARTICIPATION

9. Were there any consumers or former consumers (i.e. people who had used mental health services in the past) among the founding members of the Local Association or its steering committee?

10. Are there any consumers, or former consumers on the membership of other committees, apart from the Executive Committee?

11. Have any consumers become volunteers in the Local Association?
    YES    NO    DON'T    NO DISTINCTION BETWEEN CONSUMERS AND VOLUNTEERS
    KNOW

12. Do consumers actively participate in decision making related to their individual care and counselling.
    YES
    NO  SMALL  FAIR  CONSIDERABLE
13. Overall, do staff and volunteers consult consumers about decisions concerning the running of services shared by several consumers?

14. Overall, do consumers play an active part in decision making concerning the running of the Local Association's services and facilities?

15. Are consumers told about decisions made by the Executive Committee concerning Local Association policy?

16. Are consumers encouraged to contribute ideas and suggestions about Local Association policy?

17. Do most Executive Committee members, staff and volunteers take seriously consumers' own assessments and perceptions of their needs?

18. Do consumers start self help groups or other services within the Local Association?

19. Does the Local Association draw to the attention of National MIND or Albion Region MIND the rights and needs of particular individuals or groups of consumers?

20. Are consumers encouraged by staff and volunteers to advocate their own needs and rights (self advocacy)?

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<th>NO</th>
<th>SMALL</th>
<th>FAIR</th>
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21. Does the Local Association urge professionals to encourage or enable consumer participation in statutory services?

22. Does the Local Association urge local councillors, M.P.s or other politicians to consult consumers about their views and needs, or offer explanations about mental health policies?

23. How much consumer participation is there in each of the following functions or services of the Local Association? (RECORD NUMBER OF CONSUMERS INVOLVED IN EACH)

<table>
<thead>
<tr>
<th></th>
<th>NO</th>
<th>SLIGHT</th>
<th>FAIR</th>
<th>CONSIDERABLE</th>
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<tbody>
<tr>
<td>a) Advice and information for consumers or their relatives on mental health and welfare issues</td>
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<td>b) Provision of other services for consumers or their relatives</td>
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<td>c) Fund raising activities</td>
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<td>d) Education and information on mental health issues for general public or professionals</td>
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<tr>
<td>e) Publicity of the Local Association and of mental health issues</td>
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<tr>
<td>f) Campaigning for improvements in statutory mental health services</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>g) Advocacy and representation of consumers' rights and needs</td>
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<td></td>
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<tr>
<td>h) Other functions or services (e.g. those mentioned by respondent)</td>
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24. Can you think of examples of consumer participation (consumers being involved in decision making or taking on responsibility) which have a) worked well; b) resulted in difficulties for individuals or for the Local Association?

25. What factors enable, or mitigate against consumer participation in MIND/Association for Mental Health?

26. 
   a) What do you see as the most important objectives of: i) National MIND; (ii) Regional MIND?
   b) Are there any objectives of National and Regional MIND with which - MIND/Association for Mental Health particularly agree or disagree?

E. RECENT CHANGES

27. What do you feel are the advantages and disadvantages of being affiliated to National MIND?

28. 
   a) How effective do you think Forum is in representing the views of Local Association members to National MIND?
   b) What do you think of the proposed new structure for Local Associations?

29. To what extent do (i) National MIND (ii) Regional MIND communicate with the Local Association on the following:
   a) Provision of services for consumers
   b) Fund raising
   c) Education and information for general public and professionals
   d) Consumer participation
   e) Publicity
   f) Advocacy of consumers' rights and needs
   g) Campaigning

<table>
<thead>
<tr>
<th>NIL</th>
<th>SMALL</th>
<th>FAIR</th>
<th>CONSIDERABLE</th>
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710
30. To what extent does Albion Regional MIND communicate with the Local Association on the following:

a) Provision of services for consumers
b) Fund raising
c) Education and information for general public and professionals
d) Consumer participation
e) Publicity
f) Advocacy of consumers' rights and needs
g) Campaigning

31. To what extent does the Local Association communicate with (i) National MIND; (ii) Regional MIND on the following?

a) Provision of services for consumers
b) Fund raising
c) Education and information for general public and professionals
d) Consumer participation
e) Publicity
f) Advocacy of consumers' rights needs
g) Campaigning
32. How much impact and influence do you think the views of Local Association participants have on: (i) National MIND policies; (ii) Regional MIND policies on:

| a) Provision of services for consumers. |
| b) Fund raising. |
| c) Education and information for general public and professionals. |
| d) Consumer participation. |
| e) Publicity. |
| f) Advocacy of consumers' rights and needs. |
| g) Campaigning. |
APPENDIX 1.7

INTERVIEW SCHEDULE 7

QUESTIONS FOR ALL PARTICIPANTS IN EASTVALE AND WESTHILL MIND

Day centre/club members, Executive Committee participants and staff members were all asked questions listed in this interview schedule.

SECTION A

BOTH LOCAL ASSOCIATIONS

1. What do you see as the most important aims and objectives of:
   a) Eastvale/Westhill MIND;
   b) Albion Regional MIND;
   c) National MIND?

2. What are your views, if any, of the work of:
   a) Eastvale/Westhill MIND;
   b) Albion Regional MIND;
   c) National MIND?

3. In Eastvale/Westhill MIND, what factors, in your view:
   a) Facilitate day centre/club members' participation in decision making and responsibility.
   b) Mitigate against their participation and taking on responsibility?

4. Do you think there is too much, too little, or sufficient involvement of the following groups of people on the Executive committee:
   a) mental health professionals;
   b) day centre/club members;
   c) lay people?

5. To what extent does the Executive committee consult day centre/club members about their views?
   0 NIL    1 SLIGHT  2 FAIR  3 MARKED  4 VERY CONSIDERABLE
6. To what extent do you think Eastvale/Westhill MIND campaigns for improvements in local statutory services?

   0   1   2   3   4
   NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

b) Do you think Eastvale/Westhill MIND is sufficiently involved in campaigns for improvements in local statutory services?

7. To what extent do you think people with mental health problems, such as day centre/club members, should have a say in National MIND policies?

8. Overall, how much influence do you think day centre/club members have on National MIND policy?

   0   1   2   3   4
   NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

9. Overall, how much influence do you think day centre/club members have on local statutory policies?

   0   1   2   3   4
   NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

10. Can you think of specific examples of consumer participation within Eastvale MIND which have:

a) been particularly beneficial to individuals or to the organisation as a whole;

b) resulted in problems for individuals or for the Local Association as a whole;

11. What, if any, have been:

   a) the advantages and benefits;

   b) the disadvantages and problems, of Eastvale MIND day centre members' participation and taking on responsibility:

   (i) in the day centre;
   (ii) in fund raising and other activities;
   (iii) serving on subcommittees; e.g. fund raising, computer;
   (iv) serving on the Executive committee?
12. Overall, how much influence do you think day centre members have on the making of important decisions of Eastvale MIND?

0  NIL  1  SLIGHT  2  FAIR  3  MARKED  4  VERY CONSIDERABLE

SECTION C
WESTHILL MIND

13. a) In what ways, if any, have club members benefited from responsibility/involvement in decision making?

b) In what ways, if any, did their responsibility/involvement in decision making have negative consequences for: (i) themselves; (ii) other people in Westhill MIND?

c) In what ways, if any, did club members' taking on responsibility/involvement in decision making benefit other people in Westhill MIND?

14. a) Do you think there are too many, too few, or about the right number of the following groups of people on Westhill MIND's Executive Committee:

i) mental health professionals;

ii) lay people?

b) Do you think that Westhill MIND's Executive Committee should include people who have, themselves, experienced mental health problems? What is the reason for your answer?

15. a) To what extent do you think Executive Committee and other members of Westhill MIND consult club members about their views?

0  NIL  1  SLIGHT  2  FAIR  3  MARKED  4  VERY CONSIDERABLE

b) Do you think that Executive Committee members of Westhill MIND should involve club members more in decision making, or not?
16. a) To what extent do you think Executive Committee members consult the views of volunteers and other club members?

a) Volunteers

(i) 0 1 2 3 4
NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

(ii) NOT ENOUGH ENOUGH TOO MUCH

b) Other club members

(i) 0 1 2 3 4
NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

(ii) NOT ENOUGH ENOUGH TOO MUCH

17. To what extent are volunteers and other club members involved in taking on responsibility in Westhill MIND?

a) Volunteers

(i) 0 1 2 3 4
NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

(ii) NOT ENOUGH ENOUGH TOO MUCH

b) Other club members

(i) 0 1 2 3 4
NIL SLIGHT FAIR MARKED VERY CONSIDERABLE

(ii) NOT ENOUGH ENOUGH TOO MUCH
APPENDIX 1.8

INTERVIEW SCHEDULE 8

QUESTIONS FOR EXECUTIVE COMMITTEE MEMBERS IN EASTVALE AND WESTHILL MIND

SECTION A: QUESTIONS FOR BOTH LOCAL ASSOCIATIONS

1. How long have you: a) been actively involved in Eastvale/Westhill MIND; b) occupied the post of - (ADD TITLE OF OFFICER/MEMBER POST).

2. What do you see as the most important aspects of your post of -?

3. Overall, to what extent would you say that Eastvale/Westhill MIND agrees or disagrees with the objectives of:
   a) National MIND;
   b) Regional MIND?

4. a) To what extent do members of the Local Association communicate with National and Regional MIND?
   b) Which people in the Local Association usually communicate with National and Regional MIND?

   CHECKLIST

   CHAIRPERSON
   SECRETARY
   TREASURER
   STAFF MEMBER
   OTHER PEOPLE

5. Which people in the Local Association receive most of the correspondence from: 1 Regional; 2 National MIND?

6. a) Overall, do you think the Association has sufficient influence on: a) regional; b) national MIND policies?
   b) On which aspects of MIND's work at regional and national levels do you think - association has most influence?

7. Can I ask why you originally became involved in the work of - Local Association?
8. Please would you mind if I check what sort of work you've been involved in? (I'm interesting in comparing the answers of Executive Committee members with and without a background in a mental health profession).

9. Do you think there are too many, too few, or about the right number of the following groups of people on the Executive Committee:
   a) Day centre/club members;
   b) Other lay members;
   c) Mental health professionals?

SECTION B: QUESTIONS FOR EASTVALE MIND EXECUTIVE COMMITTEE

10. For what reasons was it decided to:
   a) Include Day Centre members in the Executive Committee;
   b) Have Day Centre members as stewards;
   c) Involve Day Centre members on the fund raising subcommittee and in fund raising activities.
   d) Involve Day Centre members on the computer subcommittee?

11. a) Have any Day Centre members occupied the posts of Chairperson, Vice Chairperson, Secretary or Treasurer?
   b) (IF ANSWER TO 1a) is NO, OR RARELY) Why have so few/no Day Centre members occupied these posts?
   c) Do you think it would be possible, or not, for Day Centre members to:
      (i) take on posts of Chairperson, Secretary or Treasurer?
      (ii) run the Local Association themselves, including the occupation of all officer and staff posts?
      (iii) make applications to funding bodies? (PROMPT, WOULD SUCH, APPLICATION BE TAKEN SERIOUSLY BY FUNDING BODIES?)

12. Are there any decisions made by the Local Association in which you feel Day Centre members could not, or should not, be involved?

13. To what extent are Day Centre members on the Executive Committee involved in:
   a) the appointment of staff;
   b) the dismissal of staff?

14. Have there been any decisions made by the Executive Committee with which a majority of Day Centre members did not agree?
15. a) In the Local Association, which groups of people (i.e. Day Centre members, officers, staff, Executive Committee members, co-opted members) have: 1. most influence 2. least influence in making decisions in Eastvale MIND?

b) Do you think any of these groups of people have too much or too little influence? In what ways?

c) 1. How much influence do you think you have on decision making in Eastvale MIND? 2. In what ways do you have influence?

16. (QUESTION ASKED OF SPONSORS OF FUNDING BODY).

a) At an Executive Committee meeting; you mentioned that you and - are "Sponsors". Please can you tell me what this means?

b) Does the fact that you are Sponsors mean that certain decisions can be made only by you and - ? Please can you tell me what sorts of decisions?

SECTION C WESTHILL MIND EXECUTIVE COMMITTEE MEMBERS

17. Are you on the Executive Committee as a representative of the Social Services Department/District Health Authority/other organisation; or of mental health social workers/psychiatrists/other professionals, or volunteers?

18. To what extent do you think Westhill MIND collaborates with local statutory services?

19. What do you think are the advantages and disadvantages of Westhill MIND's:

a) relatively large amount of statutory funding;

b) collaboration with statutory services on some projects?

(PROMPT. DO YOU THINK EITHER OF THESE FACTORS INHIBIT WESTHILL MIND'S CAMPAIGNING ROLE?)

20. a) To what extent is Westhill MIND influenced by: 1. Regional; 2. National MIND Policies?

b) How far is Westhill MIND able to be autonomous, in the sense of deciding on its objectives and policies, independently of statutory services, and of National and Regional MIND?

21. In its collaboration with statutory services, to what extent does Westhill MIND represent the felt needs and views of people with mental health problems?
APPENDIX 1.9
INTERVIEW SCHEDULE 9
EASTVALE MIND DAY CENTRE MEMBERS

1. a) When did you become a member of Eastvale MIND?
   b) Why did you decide to become a member?

2. What, if anything, do you a) like; b) dislike about:
   i) Eastvale MIND day centre;
   ii) other things concerning Eastvale MIND?

3. Can I check on any responsibility that you’ve taken on in Eastvale MIND?
   a) Executive Committee member.
   b) Nomination for Executive Committee membership.
   c) Steward.
   d) Offering to be steward.
   e) Fund Raising subcommittee.
   f) Computer subcommittee.
   g) Help with fund raising.
   h) Helping other members with their problems, or helping in other ways.
   i) Other (ASK TO SPECIFY).

4. ASK EITHER a) or b), DEPENDING ON WHETHER RESPONDENT HAS BEEN A STEWARD, OR NOT.
   a) NOT BEEN A STEWARD.
      i) Have you ever been asked to be a steward?
      ii) Have you ever thought of volunteering to be a steward?
      iii) Would you like to be a steward? What are the reasons for your answer.
   b) IS A STEWARD.
      i) When did you become a steward? For what reasons?
      ii) What are the things you enjoy or like about being a steward?
      iii) What are the things that you dislike about being a steward?
      iv) What problems, if any, do you encounter in your work as a steward?

5. ASK EITHER a) or b), DEPENDING ON WHETHER OR NOT RESPONDENT HAS SERVED ON THE EXECUTIVE COMMITTEE, OR A SUBCOMMITTEE.
   a) HAS NOT SERVED ON EXECUTIVE COMMITTEE OR SUBCOMMITTEE.
i) Have you ever put your name forward for nomination as an Executive Committee member or as a member of one of the subcommittees?

ii) (IF YES TO Q.5a (i)) Why do you think your nomination was unsuccessful?

b) HAS SERVED ON EXECUTIVE COMMITTEE OR SUBCOMMITTEE.

i) What do you see as the most important aspects of your work as a member of the Executive Committee/subcommittee?

ii) How long have you been an Executive Committee member?

6. To what extent do you feel the day centre members on the Executive Committee adequately represent the views and interests of other day centre members?

(PROMPT. DO YOU THINK THE DAY CENTRE MEMBERS ON THE EXECUTIVE COMMITTEE ADEQUATELY REPRESENT MEMBERS OF BOTH SEXES AND OF DIFFERENT AGES?)

7. a) How much influence do you think day centre members have in the making of decisions concerning:

i) Executive Committee decisions about Eastvale MIND?

NOT ENOUGH TOO MUCH DON'T KNOW OTHER RESPONSE

ii) The day to day running of the day centre?

NOT ENOUGH TOO MUCH DON'T KNOW OTHER RESPONSE

iii) Fund raising?

NOT ENOUGH TOO MUCH DON'T KNOW OTHER RESPONSE

(iv) The computer?

NOT ENOUGH TOO MUCH DON'T KNOW OTHER RESPONSE

(v) The new accommodation project?

NOT ENOUGH TOO MUCH DON'T KNOW OTHER RESPONSE
7. b) (If answer is "NOT ENOUGH" to any of the above).

In what ways do you think day centre members should be more involved?

8. a) Which people do you think have the most say in making important decisions within MIND?

CHECKLIST

* SECRETARY.
* DAY CENTRE MEMBERS NOT ON EXECUTIVE COMMITTEE AND NOT STEWARDS.
* DAY CENTRE MANAGER.
* CO-OPTED MEMBERS OF EXECUTIVE COMMITTEE. (Give examples).
* YOURSELF.
* CHAIRPERSON.
* DAY CENTRE MEMBERS ON THE EXECUTIVE COMMITTEE.
* OTHER MEMBERS OF THE EXECUTIVE COMMITTEE.
* "BEN" (DAY CENTRE MEMBER REPRESENTATIVE).
* TREASURER.
* STEWARDS WHO ARE NOT ON THE EXECUTIVE COMMITTEE.

b) Do you think any of these people have: (i) too much of a say; (ii) not enough say in making decisions in Eastvale MIND? Why is that?

c) Would you like to have more of a say in making decisions in Eastvale MIND: (If "YES") In what ways?

d) In what ways, if any, have you tried to influence Eastvale MIND policies about decision making? How successful were you in influencing policies and decision making?

9. a) Have you been involved in starting, or joining any self help groups for people who have experienced similar problems to yourself? Is this something you'd like to be involved in?

b) Would you like to be actively involved in planning and starting other facilities for people with mental health problems?
c) What do you think of organised groups of people with mental health problems who criticise health and social services provision, and who campaign for improvements and changes in services? Have you been a member of such a group? Would you like to be?

10. Have you been involved in any way in any local plans for mental health services (eg. those made by the District Planning Team or other bodies)?

a) Receiving explanations about plans for mental health services in Eastvale.

YES NO DON'T KNOW

b) Being asked about your views and opinions by members of the planning team(s).

YES NO DON'T KNOW

c) Active involvement in the planning team(s).

YES NO DON'T KNOW

11. Did you know that:

a) MIND is a National organisation with a Head Office in London;

b) That besides Eastvale MIND, there are other local branches, of MIND?

c) And regional offices, including one in Midbury?

12. To what extent would you like to have a say in National MIND policies?
APPENDIX 1.10

INTERVIEW SCHEDULE 10

WESTHILL MIND CLUB MEMBERS

In addition to the questions in this schedule, Westhill MIND club members were asked other questions. These have not been included because they were on topics not covered in the thesis.

(This schedule is in three sections: questions asked of members of both the clubs studied; and in Delta Club and Zeta Club).

SECTION A: BOTH CLUBS

1. (If APPROPRIATE). Do you see your role in the club mainly as a club member, or as a volunteer, or both?

2. a) When did you become a member/volunteer of the club?
    b) Why did you decide to become a member/volunteer?
    c) (If A VOLUNTEER) What do you see as the most important aspects of your work as a volunteer?

3. What, if anything, do you: a) like, b) dislike about the club?

4. a) In what ways if any, do club members benefit from taking on responsibility and being involved in decision making in the club?
    b) In what ways, if any does their responsibility or involvement in making decisions have negative consequences for: 1. themselves; 2. other club members?
    c) In what ways does club members' taking on responsibility benefit other club members?

5. a) What do you see as the main activities of the club?
    b) Do you think the club should have any other activities? (If YES). What activities?

6. a) What do you see as the main aims of the club?
    b) Are there any other aims that you think the club should have?
(Alpha Club was a social club on a housing estate which was initially facilitated by a Westhill MIND staff member and a statutory social worker).

7. a) Do you think there is anyone who is a leader or organiser of the club?

b) Which person or persons do you think have been most involved in making important decisions about the club and its activities?

CHECKLIST

PARTICULAR CLUB MEMBERS
(STATUTORY) SOCIAL WORKER
WESTHILL MIND STAFF MEMBER

c) Do you think all club members are involved enough in the making of important decisions in the club?

d) Do you think you are sufficiently involved in the making of important decisions in the club?

8. a) Whose idea do you think it was to start the club?

b) Which people were involved with the club when it started?

(PROMPT: TO WHAT EXTENT WERE THE FOLLOWING INVOLVED?)

LOCAL PEOPLE
PRESENT CLUB MEMBERS
(STATUTORY) SOCIAL WORKER
FORMER MIND DEVELOPMENT WORKER OTHER PEOPLE.

9. a) Do you take on any sort of responsibility within the club?

(PROMPT, IF NECESSARY, WITH EXAMPLES GIVEN IN Q10).

b) (IF APPROPRIATE) What do you like or dislike about being a volunteer/taking on responsibility in the club? (PROMPT - ANY PARTICULAR REWARDS OR PROBLEMS?).

10. To what extent do you think club members are involved in:
a) Helping each other with problems.
b) Making suggestions about activities.
c) Organising activities.

(PROMPT - HAVE b) and c) COME MAINLY FROM STATUTORY SOCIAL WORKER, FORMER MIND STAFF MEMBER, A VOLUNTEER OR MEMBERS?).

d) Fund raising (Has this been for the club and/or Westhill MIND?).
e) Looking after the finances of the club.
f) Keeping the centre clean and tidy. (Is a caretaker mainly responsible?).
g) Preparing refreshments.
h) Taking care of keys. Locking and unlocking the club premises/centre.

Is there any other area of responsibility that members have been involved in, in the club?

11. Have members of the club been involved at all in:

a) Publicising the club.
b) Contacting the local council and other bodies about the meeting place and other matters concerning the club. (PROMPT - WHO ARRANGED THE MEETING PLACE WITH THE COUNCIL?).

c) Campaigning for improvements in amenities on the Estate.
d) Campaigning for improvements in mental health services.
e) Advocating the needs of club members, or of people with mental health problems generally.
f) Explaining to the public, or to professional people and students, about the club.
g) Educating members of the public, professionals or students about mental health problems.

12. Has the club ever had:

a) A clearly defined leader.
b) Chairperson, secretary or treasurer posts, or any sort of management committee?

13. a) Is the club open to anyone to join? (Prompt - all age groups? Have all members experienced mental health problems?).
b) How successful do you think the club has been in getting new members?
14. Do you think the club is connected with Westhill MIND in any ways? If so, in what ways?

(Prompt, if necessary - Former Development worker’s involvement. Involvement by other MIND member. Other ways).

15. Do you see yourself as belonging to Westhill MIND because of your membership of the club?

16. Are you, or have you been involved with Westhill MIND in any (other) way?

a) Phoned the Resource Centre.
b) Visited the Resource Centre.
c) Attended Zeta club or other social events or clubs.
d) Spoke to staff or to other people involved with Westhill MIND.
e) Attended AGMs or other meetings.
f) Helped with Fund Raising.
g) Involvement as a volunteer in other ways.
h) Other involvement.

17. Would you like to take on (more) responsibility within Westhill MIND, or not? If Yes, in what ways?

a) As a volunteer: e.g. in social clubs, group homes, fund raising, helping in office.
b) As an Executive Committee member (EXPLAIN, IF NECESSARY).
c) As a member of staff?

Is there any other way in which you would like to take on responsibility within Westhill MIND?

18. (IF NO to 17a, b or c) Can I ask why not? b (if Yes to 17a, b or c) What do you feel you could contribute as a volunteer/Executive Committee member/staff member?

19. Do you know of any members of the club who are, or have been, involved in any way in:

a) Taking on responsibility within WESTHILL MIND, e.g., as a volunteer.
b) Making decisions within WESTHILL MIND?

(PROMPT - Ask for details of responsibility/decision making).
20. (If YES to 10.19 a or b)
   a) In what ways, if any, did club member(s) benefit from this responsibility/involvement in decision making?
   b) In what ways, if any, did their responsibility/involvement in decision making have negative consequences for: 1. themselves; 2. other people in Westhill MIND?
   c) In what ways, if any, did club members' taking on responsibility/involvement in decision making benefit other people in Westhill MIND?

21. (IF APPROPRIATE).
   a) Would you like to have more of a say in making important decisions in Westhill MIND? If yes, in what areas?
   b) In what ways, if any, have you tried to influence decisions in Westhill MIND? How successful were you in influencing these decisions?

SECTION C. ZETA CLUB MEMBERS

22. To what extent, if at all, do you think there is a distinction between "volunteers" and other members of the club?

23. Do you think a) club members, b) volunteers have enough of a say in 1) the making of important decisions in WESTHILL MIND? 2. have enough responsibility in WESTHILL MIND?

24. Recently a "consumer advisory panel" has been proposed to advise National MIND about the views and needs of people who have themselves experienced mental health problems. What do you think of the idea of a consumer advisory panel?

25. a) Which of the present members/volunteers were involved in the club in its early days?
   b) Which person has been involved in the club the longest?
   c) Whose idea was it to start the club?
   d) Who ran the club in its early days?
e) At this time who was involved in decision making in the club? To what extent was there a distinction between "members" and "volunteers?"

26. a) Do you see yourself as being a member of MIND?
   b) Do you mind if I ask if you are a member of MIND in the sense of paying a subscription?

27. Who in the club is mainly responsible for:
   a) Organising activities.
   b) Unlocking the centre/locking up. (Which members/volunteers have keys to the centre?)
   c) Looking after the club's finances?
   d) Is there anyone who has particular responsibilities in anything else?

28. In what ways have you been involved in Westhill MIND:
   a) Membership of other clubs or support groups.
   b) Attending the AGM's.
   c) Attending Executive Committee meetings, open meetings, or other meetings.
   d) Attending the recent course for volunteers.
   e) Attending other meetings for volunteers.
   f) Helping with fund raising.
   g) Involvement as a volunteer in other ways.
   h) Other involvement.

29. a) When did (i) the Sunday club, (ii) the Friday lunch club start?
   b) Who decided to start these clubs?
   c) Is anyone responsible for "organising" or "running these clubs?"
   d) What do you see as the most important aims of these clubs?
APPENDIX 1.11
INTERVIEW SCHEDULE 11
LOCAL ASSOCIATIONS WITH HIGH CONSUMER INVOLVEMENT

In addition to the questions in this schedule, respondents in Local Associations with high consumer involvement were asked other questions. These are not included because they were on topics which are not covered in the thesis.

1. a) What are the main aims of MIND?
   b) What are the main projects of MIND?
   c) Does MIND receive any statutory funding?

2. To what extent does the Local Association:
   a) Make a distinction between people who give help and people who receive help; or:
   b) See everyone in MIND as able to give help at times, and needing help at times?

3. Do people in the Local Association:
   a) See people who have experienced mental health problems as a clear category of people with different experiences to most of us; or:
   b) Regard everyone as having experienced mental health problems or severe distress, or having the potential to do so?

4. a) What is your understanding of the terms:
   (i) consumers;
   (ii) consumer involvement?
   b) What do you like to call people who have experienced mental health problems?

5. a) Overall, to what extent are consumers involved in responsibility and decision making in MIND?
   b) In your view, how does MIND compare with other Local Associations in terms of consumers' involvement in responsibility and decision making?

6. To what extent are the following groups of people involved in decision making and important responsibility in the organisation, overall:
   a) People who see themselves as having experienced mental health problems.
b) People who are mental health professionals (and not involved in MIND primarily because of their own mental health problems).

c) Lay people who do not see themselves, or their relatives, as having experienced mental health problems.

d) Lay people who view their relatives as having experienced mental health problems.

7. a) (RESPONDENTS WITH CONSUMER EXPERIENCE ONLY):

(i) In what ways are you involved in decision making and responsibility in the organisation?

(ii) What benefits, if any, do you get from this decision making and responsibility?

(iii) In what ways, if any, does it cause you problems?

b) (ALL RESPONDENTS)

In what ways has consumer involvement in MIND been?

(i) beneficial to the individual;

(ii) caused problems to the individual;

(iii) beneficial to the organisation;

(iv) caused problems to the organisation?

8. Were there any consumers among the founding members of the Local Association?

9. a) To what extent are the following groups of people on the Executive Committee?

b) In your view, to what extent should members of each of these groups be on the Executive Committee?

(i) People who see themselves as having experienced mental health problems.

(ii) People who are mental health professionals (and not involved in MIND primarily because of their mental health problems.)

(iii) Lay people who do not see themselves or their relatives as having experienced mental health problems.

(iv) Lay people who view their relative(s) as having experienced mental health problems.

10. a) Are any members of the Local Association with personal experience of mental health problems members of:

(i) Forum.

(ii) the Regional Advisory Committee/Regional Council.

(iii) Council of Management?
b) To what extent do you think people with personal experience of mental health problems should be members of the above and the Consumer Advisory Network?

c) (RESPONDENTS WITH CONSUMER EXPERIENCE ONLY) Would you like to be a member of: (i) any of the above; (ii) the consumer advisory network or not?

11. a) Are you satisfied with the extent to which you, and/or other consumers are involved in decision making and responsibility in:

(i) the local association;
(ii) regional MIND
(iii) national MIND?

b) (RESPONDENTS WITH CONSUMER EXPERIENCE ONLY IF ANSWERS NO). In what ways would you like to be more involved?

12. a) (EMPLOYED STAFF ONLY)

(i) Can I ask to what extent - MIND has an Equal Opportunities Policy?

(ii) To what extent do you think - MIND would be prepared to employ staff with personal experience of mental health problems?

b) (RESPONDENTS WITH CONSUMER EXPERIENCE ONLY).

(i) Would you like to be a staff member at local, regional or national levels?

(ii) (IF ANSWERS "YES") What do you think you could contribute to MIND?

13. a) To what extent is there consumer involvement in the following?

(i) Projects (e.g. day centre, club).
(ii) Campaigning.
(iii) Publicity/education.
(iv) Fund raising.

b) Is there considerable consumer involvement in any other activities of - MIND?
14. How much contact do: a) yourself; b) other members of the Local Association have with the following?

(i) Local Councillors.
(ii) Local MP's.
(iii) Other politicians (which ?)
(iv) Members of the DHA.
(v) Members of the RHA.
(vii) Other people/bodies which respondent thinks important.

15.a) Are: a) yourself; b) (other) members of the Local Association have with the following?

(i) Community Health Council.
(ii) DHA Planning Team.
(iii) RHA Planning Team.
(iv) Joint Consultative Planning Team.
(v) Social Services Planning Team.
(vi) Other planning teams/committees.

b) (IF YES TO ANY OF ABOVE) Are you serving: (i) as a representative of MIND; ii) in your own right?

16. Within - MIND, what factors, in your view:

a) facilitate consumer involvement in decision making and taking on responsibility?

b) mitigate against consumer involvement in decision making and responsibility?

17. Can I ask:

a) Why you originally became involved in - MIND?

b) (RESPONDENTS WITH CONSUMER EXPERIENCE ONLY) Why you became actively involved in decision making and responsibility in the organisation?

18. To what extent do you think it would be: a) possible; b) desirable, for consumers to themselves run: (i) - MIND; (ii) National MIND?

19. a) Has: (i) the Regional Office; (ii) National MIND issued any guidelines about consumer involvement?

b) In your view, does (i) Regional MIND; (ii) National MIND have clear objectives in relation to consumer involvement?

c) How committed would you say: (i) Regional MIND; (ii) National MIND are to consumer involvement?
d) Has Regional/National MIND promoted or encouraged consumer involvement in any way?

20. How important is consumer involvement, as an issue, compared with other topics, in the communication of:

a) Regional MIND to the Local Association.
b) The Local Association to Regional MIND.
c) National MIND to the Local Association.
d) The Local Association to National MIND?

21. To what extent is the Local Association influenced by ideas about consumer involvement from: a) Regional MIND; b) National MIND?

22a. In the Local Association, who decided that there should be high consumer involvement?

CHECK LIST

ASSESS INFLUENCE OF: CONSUMERS OTHER MEMBERS OF STEERING COMMITTEE/EXECUTIVE COMMITTEE REGIONAL MIND REGIONAL MIND COMMUNITY DEVELOPMENT OFFICER.

22b. Why was it decided that there should be high consumer involvement in MIND?
APPENDIX 1.12

INTERVIEW SCHEDULE 12

MEMBERS OF CAMPAIGN AGAINST PSYCHIATRIC OPPRESSION

1. Besides the items listed in the Declaration of Intent, does Campaign Against Psychiatric Oppression (CAPO) have any other aims?

2. a) Who wrote the "Introduction, Manifesto, Demands"?
   b) Whose views does this document represent?
      (CHECK: MEMBERS OF CAPO
      OTHER EX-"VICTIMS").

3. a) When was CAPO founded?
   b) Who founded it?

4. a) How many members are there in CAPO?
   b) Have all members: (i) received psychiatric treatment;
      (ii) been inpatients?
   c) Is it possible for mental health professionals, or other interested people to be members?

5. Do you believe that all psychiatrists are conscious "agents of capitalism" and "high priest(s) of technological society"? Quotes from CAPO's "Introduction, Manifesto, Demands".

6. a) To what extent does CAPO "take collective action" with Trade Unions, Claimants' Unions, etc?
   b) In what ways does it take collective action?

7. To what extent do you/will you:
   a) advise people about their rights; (in what ways?).
   b) campaign on banning ECT, long-acting drugs, psychosurgery;
   c) campaign for financial compensation for tardive dyskinesia;
   d) enable patients to receive free legal aid?
8. To what extent have members of CAPO inspected psychiatric institutions?

9. a) To what extent does CAPO aim to influence: (i) Central Government; b) Local Government policy making for mental health services?

b) Are there any politicians (e.g., M.P's members of the House of Lords) who are particularly supportive towards CAPO and its aims?

c) How much contact does CAPO have with senior civil servants and politicians?

10. a) To what extent do you think the views of CAPO represent the views of most psychiatric inmates/ex-inmates.

b) To what extent are they meant to be representative?

11. a) To what extent does CAPO aim to influence attitudes and beliefs about so-called "mental illness" and its treatment?

b) How does CAPO propose to go about doing so?

CHECKLIST
RESEARCH
EDUCATION FOR PROFESSIONALS
EDUCATION FOR GENERAL PUBLIC
OTHER

c) Are there any professionals who are sympathetic to CAPO and its aims?

12. To what extent are all members involved/encouraged to be involved in: a) important decision making; b) taking on responsibility in CAPO?

13. In what ways, if any, is members' involvement in decision making and responsibility:

a) beneficial to the individual;

b) cause problems to the individual;

c) beneficial to the organisation;

d) cause problems to the organisation?

14. Are there any organisational factors which facilitate or mitigate against members' involvement in decision making and responsibility?

15. a) Is CAPO represented on any Planning Teams or other organisations?

b) Would you like such representation?
16. Are there any ways in which CAPO would consider working in close collaboration with mental health professionals and statutory services (e.g. to "improve" the system)?
1. What do you see as the main aims of Depressives Anonymous: a) nationally; b) locally?

2. a) Who founded Depressives Anonymous, and when?
b) Is (s)he still involved in Depressives Anonymous?

3. a) Have all members of Depressives Anonymous experienced depression?
b) Is Depressives Anonymous for people will all kinds of depression?
c) Are there any members who are relatives?

4. Can I ask the reasons why:
a) You became involved in Depressives Anonymous;
b) You became a member/officer of the Executive?

5. To what extent does Depressives Anonymous have the following aims and functions: a) in Westhill; b) nationally?

   (i) acting as a pressure group; drawing to the attention of politicians and others the needs and interests of people with depression;

   (ii) campaigning for improvements in services and/or professional understanding of depression and its treatment;

   (iii) other political activities: e.g. lobbying politicians.

   (iv) collaboration with local statutory services, e.g. projects.

   (v) advocacy of the needs and rights of people with depression;

   (vi) providing a counselling and/or advice services.

6. a) How are major decisions made in local groups of Depressives Anonymous?
b) To what extent are all members involved in (i) important decision making; (ii) taking on responsibility within the organisation?
7. In what ways, if any, do members' involvement in decision making and taking on responsibility:
   a) benefit themselves and other members of the group;
   b) cause problems to themselves and other members of the group?

8. a) In what ways do you benefit from being an officer/member of Depressives Anonymous?
   b) In what ways has being an officer/member caused you problems or difficulties (specifically related to your depression)?

9. Are there any factors which facilitate or mitigate against Depressives Anonymous members' involvement in decision making and taking on responsibility?

10. Does Depressives Anonymous in: a) Westhill; b) other parts of the country, have representatives on:
    a) planning teams for mental health services;
    b) community health councils;
    c) MIND Local Associations;
    d) Other organisations or bodies?

11. a) To what extent does Depressives Anonymous agree or disagree with professional (e.g. medical) views about the cause or treatment of depression?
    b) To what extent, if at all, does Depressives Anonymous see itself as working with professionals, or supporting professional viewpoints?
    c) To what extent does Depressives Anonymous provide information for professionals?
    d) Are there any professionals who act in an advisory capacity to Depressives Anonymous?

12. a) Why is there an emphasis on anonymity in Depressives Anonymous?
    b) Do all members see themselves as "depressives"?
    c) Does Depressives Anonymous, as an organisation, hold the view that someone who's suffered depression is always a "depressive"?
APPENDIX 1.14

INTERVIEW SCHEDULE 14

MEMBERS OF THE MANIC DEPRESSION FELLOWSHIP (A BRANCH IN LONDON)

1. What do you see as the most important aims of a) the Manic Depression Fellowship (MDF); b) your role in it?

2. a) When was the MDF founded?  
b) Who first thought of the organisation?  
c) Were you among the founding members?

3. Are people with experience of hypomania and/or endogenous depression described as “sufferers” in the MDF?

4. How many of the founding members were:
   a) sufferers;  
   b) relatives of sufferers;  
   c) mental health professionals;  
   d) lay people who did not see themselves as having experienced mental health problems?

5. To what extent does the MDF:
   a) act as a pressure group: drawing to the attention of politicians and others the needs and interests of people with manic depression;  
   b) campaign for improvements in services and/or professional understanding of manic depressive psychosis and its treatment;  
   c) other political activities: e.g. lobbying politicians.  
   d) collaboration with local statutory services, e.g. on projects;  
   e) advocacy of the needs and rights of people with manic depression?

6. To what extent are all sufferers involved in: a) important decision making; b) taking on responsibility within the organisation?
7. In what ways, if any, is sufferers' involvement in decision making and responsibility:
   a) beneficial to the individual;
   b) cause problems to the individual;
   c) beneficial to the organisation;
   d) cause problems to the organisation?

8. (IF RESPONDENT HAS PERSONAL EXPERIENCE OF MANIC DEPRESSIVE PSYCHOSIS) What benefits and problems have you experienced from involvement in decision making and responsibility in the MDF?

9. Are there any organisational factors which facilitate or mitigate against sufferers' involvement in decision making and responsibility?

10. Are you or other members of the MDF members of:
   a) planning teams for mental health services;
   b) community health councils;
   c) other organisations or bodies;
   d) involved in Central Government planning for mental health services (e.g. Royal Commissions, committees of enquiry)?

11. To what extent does the MDF aim to:
   a) work in close collaboration with mental health professionals and statutory services; and/or:
   b) where necessary, criticise mental health professionals and statutory services?

12. To what extent do members of the MDF: a) question, oppose or criticise; b) support and agree with present psychiatric ideas about the nature of mental illness and its treatment?

13. In your view, to what extent is there: a) a similarity; b) a difference or conflict between the needs and views of sufferers and their relatives and the MDF's serving of them?
APPENDIX 1.15

INTERVIEW SCHEDULE 15

DIRECTOR OF THE MATTHEW TRUST

1. Is The Matthew Trust involved in helping: a) present and former patients of regional secure units; b) mentally ill people in prison, beside present and former patients of Special Hospitals?

2. a) Did you start your voluntary work at Broadmoor immediately after your discharge from there in 1969?
   b) What made you decide to set up the Matthew Trust?
   c) To what extent were other former Special Hospital patients involved in setting up The Matthew Trust or taking on responsibility within the organisation?

3. a) Do you have a list of aims or objectives of The Matthew Trust?
   b) (IF NO TO 3a) What do you see as the most important aims of The Matthew Trust?
   c) How important are the following aims in The Matthew Trust?
      (i) Befriending present and former special hospital patients.
      (ii) Help with rehabilitation.
      (iii) Making grants/donations of money.
      (iv) Providing, or contributing towards, legal help for present or ex-Special Hospital patients.
      (v) Running specific projects: e.g. social centres, accommodation projects.
      (vi) Facilitating self help groups for present or ex-patients.
      (vii) Providing counselling/advice for present or ex-patients.
      (viii) Monitoring, care, treatment and aftercare of Special Hospital patients.
      (ix) Campaigning for improvements in Special Hospitals/other provision for mentally ill or mentally handicapped offenders.
      (x) Campaigning for changes in mental health law.
      (xi) Advocacy of the rights and needs of individuals in, or discharged from, Special Hospitals.
      (xii) Running educational activities for professionals.
(xiii) Educating the general public about the needs of former or present Special Hospital patients.

(xiv) Sponsoring research into conditions in Special Hospitals.

4. Do you attempt to influence local statutory authorities in any way (e.g. in relation to the provision of aftercare services for people discharged from Special Hospitals)?

5. To what extent do you meet with:
   a) local councillors;
   b) members of district and regional health authorities;
   c) senior social services department staff;
   d) members of community health councils?

6. How much contact do you have with:
   a) civil servants in the DHSS;
   b) civil servants in the Home Office;
   c) MP's;
   d) central government ministers;
   e) members of the House of Lords?

7. Do you have any links with the All Party Mental Health Group or the All Party Group for Penal Affairs?

8. Have you, or other members of The Matthew Trust been:
   a) members of Royal Commissions or Committees of Enquiry or on other Government bodies;
   b) members of DHA's/RHA's/Joint Care Planning Teams;
   c) members of Community Health Councils;
   d) involved in MIND in any way?

9. What proportion of: a) staff; b) volunteers; c) members of The Matthew Trust are former Special Hospital patients?

10. To what extent are former or present Special Hospital patients encouraged to take on responsibility and be involved in decision making within The Matthew Trust?

11. a) IF FORMER SPECIAL HOSPITAL PATIENTS ARE INVOLVED IN THE ORGANISATION). In what ways, if any, does the involvement in decision making and taking on responsibility, in the Matthew Trust, of people with experience of Special Hospitals:
   a) benefit themselves;
   b) benefit The Matthew Trust;
   c) cause problems to themselves;
   d) cause problems to The Matthew Trust?
12. In what ways do you feel that your setting up, and being Director of the Matthew Trust has:
   a) been of benefit to you;
   b) caused you difficulties?

13. (ASK IF FORMER SPECIAL HOSPITAL PATIENTS ARE INVOLVED IN THE ORGANISATION). Are there factors within The Matthew Trust which you feel facilitate or mitigate against the involvement in decision making and taking on of responsibility of former Special Hospital patients?

14.
   a) To what extent, if at all, does The Matthew Trust see itself as working closely with mental health professionals?
   b) Are there any mental health professionals who act in an advisory capacity to The Matthew Trust?
APPENDIX 1.16

INTERVIEW SCHEDULE 16

MEMBERS OF THE NATIONAL SCHIZOPHRENIA FELLOWSHIP
(WESTHILL BRANCH)

1. In your view, what are the most important aims of the National Schizophrenia Fellowship (N.S.F.).
   a) in Westhill;
   b) nationally?

2. Is the work "sufferer" usually used in the NSF to refer to people with a diagnosis of schizophrenia?

3. a) Were you one of the founding members of the Westhill branch?
   b) How many of the founding members were: (i) sufferers; (ii) relatives?

4. In a) Westhill NSF; b) Nationally, what proportion of members are:
   (i) sufferers;
   (ii) relatives of sufferers;
   (iii) mental health professionals;
   (iv) lay people who don't see themselves or their relatives as having mental health problems?

5. To what extent does the NSF: a) in Westhill; b) nationally:
   a) act as a pressure group: draw to the attention of politicians and others the needs and interests of people with schizophrenia and their families;
   b) campaign for improvements in services and/or professional understanding of schizophrenia and its treatment;
   c) other political activites: e.g. lobbying politicians;
   d) collaboration with local services: e.g. on projects;
   e) advocate the needs and rights of people with schizophrenia and their families?
6. In the Westhill branch, to what extent are sufferers involved in:
   a) important decision making;
   b) taking on responsibility within the organisation?

7. a) How many members of Westhill NSF's Executive Committee are:
   (i) sufferers;
   (ii) recovered sufferers;
   (iii) relatives;
   (iv) mental health professionals;
   (v) other people?
   b) Do you think there are not enough, enough, or too many sufferers and recovered sufferers on the Executive Committee?

8. To what extent are all members of Westhill NSF who are sufferers and recovered sufferers, involved in important decision making in Westhill NSF?
   a) relatives and other members determine sufferers' needs;
   b) other members consider sufferers' expressed needs and views;
   c) all sufferers are consulted about important decisions;
   d) all sufferers are actively involved in important decision making?

9. To what extent are sufferers involved in:
   a) important decision making in the national organisation;
   b) taking on responsibility within the national organisation?

10. In what ways, if any, is sufferers' involvement in decision making and taking on responsibility in: a) Westhill NSF; b) the NSF at national level:
    (i) beneficial to the individual;
    (ii) cause problems to the individual;
    (iii) beneficial to the organisation;
    (iv) cause problems to the organisation?

11. What organisational factors a) facilitate; b) mitigate against sufferers' involvement in decision making, and taking on responsibility:
    (i) in Westhill NSF;
    (ii) the national level of NSF?
12. What, if any, are the advantages and disadvantages of both sufferers and their relatives belonging to the same organisation?

13. a) In your view, to what extent, if any, is there: (i) a similarity; (ii) a difference or conflict between the needs and views of sufferers and recovered sufferers - and their relatives?

b) To what extent do sufferers and recovered sufferers express agreement or disagreement with the NSF’s perception of their needs, and the ways in which the organisation attempts to meet them?

(i) in Westhill NSF;
(ii) the NSF at national level?

c) What are sufferers’ and recovered sufferers’ views on the extent to which they are involved in responsibility and decision making in the organisation:

(i) in Westhill;
(ii) at national level?

14. To what extent does: a) Westhill NSF; b) the national organisation aim to:

a) work in close collaboration with mental health professionals and statutory services; and/or:

b) where necessary, criticise mental health professionals and statutory services?

15. a) To what extent does the NSF provide information for: (i) professionals; (ii) the public?

b) Do any professionals act in an advisory capacity to the NSF?

16. What are the main similarities and differences in the views of NSF and MIND:

a) at National level;

b) in Westhill?
APPENDIX 1.17

INTERVIEW SCHEDULE 17

CIVIL SERVANTS AT THE DEPARTMENT OF HEALTH AND SOCIAL SECURITY

(Civil servants were asked questions on a variety of topics which have not been considered in the thesis. The following list includes only those questions which are relevant to the issues discussed).

1. To what extent, if at all, does your work involve, or bring you into contact with:
   a) MIND at national and local levels;
   b) other voluntary organisations for mental health?

2. To what extent are there meetings between the D.H.S.S. and:
   a) consumers who are not members of an organised group;
   b) representatives of self-help groups (eg. Depressives Anonymous, Phobics Anonymous, Tranx);
   c) representatives of other organisations run by consumers for consumers (eg. Mental Patients Union, the Matthew Trust);
   d) National Schizophrenia Fellowship;
   e) MIND?

3. On what sorts of issues does MIND communicate most frequently with civil servants in the D.H.S.S. and with politicians?

4. What is the nature and types of communication between:
   a) the D.H.S.S. and MIND at National level;
   b) the D.H.S.S. and MIND at local level?

5. a) Why is MIND supported financially by Central Government?
   b) What does MIND have to offer Central Government?
6. What is your impression of the sorts of views that Central Government policy makers for mental health services have of MIND at:
   a) national level;
   b) local level?

7. a) Overall, to what extent does MIND influence Central Government policies?
   b) Overall, how much influence does MIND have on Central Government policies, compared with: (i) five years ago; (ii) ten years ago?
   c) On which Central Government policy issues does MIND exert most influence?

CHECKLIST

COMMUNITY CARE
MENTAL HEALTH LEGISLATION
MINOR TRANQUILLISER PRESCRIBING
OTHER ISSUES

8. In your view, which types of national voluntary organisations are most likely to receive Central Government funding at present?
   a) concentration on service provision or campaigning, or a mixture of both;
   b) those run by people with a professional background, or consumers, or both?

9. To what extent does MIND involve consumers in advocating their own needs and rights to:
   a) civil servants in the DHSS; b) politicians?

10. To what extent do voluntary organisations run by consumers for consumers.
    a) seek to influence Central Government policy;
    b) exert influence on Central Government?
APPENDIX 2

QUESTIONNAIRE 1

CONSUMER PARTICIPATION AND CONSUMER REPRESENTATION IN LOCAL ASSOCIATIONS IN ALBION REGION

This questionnaire was given to staff in Albion Region, during preliminary fieldwork, to assess the amount of consumer involvement in different Local Associations in the Region.

The version of the questionnaire in this Appendix contains columns below each response. In the version given to respondents, "no", "below average", "average" and "above average" were printed by the name of each Local Association, so that the appropriate response could be encircled.

QUESTIONNAIRE 1

This questionnaire contains 9 questions, each on a separate page. For each of the Local Associations listed, please decide whether the answer to each question is "No", "Yes" or "Don't Know".

For each question, please rate each Local Association by:

1. Putting a circle round "No" or "Don't Know" if this is your answer,
2. If your answer is "Yes", circling "Below Average", "Average", or "Above Average", depending on how the Local Association compares with other Local Associations in Albion Region.

In any question, if your answer is "Yes" for only one Local Association, please circle "Above Average". If you answer "Yes" for two or more Local Associations, circle "Average" if you feel there is little difference between them, or circle two or three categories if there are differences in the amount of consumer participation or consumer representation.

3. For each question, there is a space for comments if the question is inapplicable to a Local Association or if you wish to qualify your answer.
**QUESTION 1**

Do consumers actively participate in decisions related to their individual care and counselling?

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<thead>
<tr>
<th>LOCAL ASSOCIATIONS</th>
<th>AMOUNT OR EXTENT OF CONSUMER PARTICIPATION OR REPRESENTATION</th>
<th>SPACE FOR COMMENTS (Eg., Please state if inapplicable)</th>
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Overall, are consumers consulted about decisions concerning the running of services shared by several consumers (e.g. day centres, shared accommodation projects?)

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<th>AMOUNT OR EXTENT OF CONSUMER PARTICIPATION OR REPRESENTATION</th>
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QUESTION 3

Overall, do consumers play an active part in decision making concerning the running of the Local Association's services and facilities?

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<th>LOCAL ASSOCIATIONS</th>
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QUESTION 4

Are consumers encouraged to contribute ideas and suggestions related to Executive Committee policy?

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<th>AMOUNT OR EXTENT OF CONSUMER PARTICIPATION OR REPRESENTATION</th>
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**QUESTION 5**

Do consumers start self help groups or other services within the Local Associations?

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<th>LOCAL ASSOCIATIONS</th>
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Does the Local Association draw to the attention of National or "Albion" Regional MIND the rights and needs of particular individuals or groups of consumers?

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QUESTION 7

Are consumers encouraged to advocate their own needs and rights (Self Advocacy)?

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Does the Local Association urge professionals to enable consumer participation in statutory services?

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Does the Local Association urge local Councillors, MP's or other politicians to consult consumers about their views and needs?

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AIMS AND OBJECTIVES OF MIND

Source: MIND Annual Reports/Reviews 1974 - 75 to 1985 - 86.

"MIND (National Association for Mental Health) is a registered charity operating in England and Wales. It exists to promote better mental health and opportunities for personal development. It also seeks to improve voluntary and statutory mental health services and to develop the concerns and common interests of patients, families, those who provide services and the public. As a membership organisation it invites the co-operation of individuals, organisations, local mental health associations and other groups who support its basic aims.

1. To improve knowledge of mental health and the causes and consequences of mental illness and handicap.

2. To encourage and demonstrate good practice in the prevention and treatment of mental disorder and to improve access to better care, rehabilitation, education and welfare for the mentally ill and handicapped.

3. To raise the standards of existing services and to encourage new and improved forms of care and treatment.

4. To uphold the rights and meet the needs of patients, ex-patients, their relatives and mental health workers; to combat the stigma, fear and prejudice still associated with mental illness.

5. To mobilise opinion in support of mental health activities through volunteers, self-help and community groups, professional workers and the public.

6. To raise funds for the activities of MIND, its local associations and other concerned groups.

7. To sponsor research, collect and distribute information and issue publications.

8. To provide advisory, counselling and advocacy services.

9. While fulfilling its existing obligations in the field of residential care, to encourage the provision of appropriate and preferably pioneering services in the community.

10. To maintain a programme of education and training for professional mental health workers, administrators, volunteers and members of the lay public, and educationalists.
CONSUMER INVOLVEMENT IN MIND: WHO, WHY AND HOW MUCH?

This discussion paper concerns three questions:

1. **Who** are the "consumers"?
2. **Why** involve consumers?
3. **How much** consumer involvement?

1. **WHO ARE THE "CONSUMERS"?**

The term "consumer involvement" suggests that there is a distinction between those of us who are consumers of mental health services, and those of us who are not. Is this distinction helpful or valid? To what extent are we all potential or actual consumers, in the sense of experiencing some form of mental ill health at some time in our lives? If certain members of MIND are viewed as "consumers", is this creating an artificial distinction between different people in the organization?

2. **WHY INVOLVE CONSUMERS?**

If we use the term "consumers" to apply to those of us who have experienced mental health problems, what efforts have been made to find out if we want to be more involved in MIND? Did the idea for this workshop come from those of us who use MIND services? How many of us here today see ourselves as "consumers"?

Whether "why involve consumers?" is a relevant question to any Local Association depends partly on the amount of distinction between "helper" and "helped", and the extent to which each member is seen as having a valuable contribution to make, and wishes to be involved. To what extent should involvement of everyone in decision making be encouraged if some Local Association members only want to meet together, and have a cup of tea in peace?
3. HOW MUCH CONSUMER INVOLVEMENT?

Ideas about the degree to which consumers should be involved depend partly on:

a) Local Association members' views of the aims of MIND; b) what they feel constitutes appropriate consumer involvement. E.g. if members of Local Association A see their main aim as providing services for passive recipients who do not wish to participate, consumer involvement might consist of everyone being told about decisions made entirely by a ("non-consumer") Executive Committee. In contrast, in Local Association B which has consumer self advocacy as its main aim, consumer involvement might consist of active participation of all members in important decision making, or perhaps, enabling the organisation to become one that is run by consumers for consumers. The attached Diagram illustrates different degrees of Consumer Involvement.

A further question is what levels of Consumer Involvement are seen as appropriate? Should Consumer Involvement be limited to decisions affecting members of Local Association projects such as social clubs, or should it extend to local Executive Committee, Regional or National levels of MIND?

CONSUMER INVOLVEMENT BEYOND MIND?

Finally, should the influence of those of us who are consumers extend beyond the organisation? Should it include attempts to influence decisions about mental health services made by Local and Central Government? The answer to this question depends partly on the extent to which a Local Association sees itself as a campaigning organisation. We may all increase our involvement in decision making within MIND, but to what extent will this, and should this, extend to influence policies and provision of statutory services?

Richard Byrt
<table>
<thead>
<tr>
<th>Degree of Consumer Involvement</th>
<th>Degree</th>
<th>Type of Consumer Involvement</th>
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<tr>
<td>Low Low</td>
<td>1</td>
<td>0: <strong>NIL</strong></td>
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<td>All decisions are made entirely by non-consumers, who do not explain their decisions to consumers, or otherwise involve them in decision making. Clear distinction between consumers and non-consumers.</td>
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<td><strong>EXPLANATION</strong></td>
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<td>Non-consumers provide consumers with information, and explanation of their decisions, but do not otherwise involve consumers in decision making.</td>
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<td><strong>CONSULTATION</strong></td>
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<td>Non-consumers ask consumers their views and opinions, and take these into account when making decisions.</td>
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<td><strong>DIRECT REPRESENTATION</strong></td>
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<td>One or more consumers, representing consumer opinion, are actively involved in decision making.</td>
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<td><strong>EQUAL PARTICIPATION</strong></td>
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<td>Consumers and non-consumers are equally involved in decision making. Little or no distinction between &quot;consumers&quot; and &quot;non-consumers.&quot;</td>
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<td>5</td>
<td><strong>TOTAL RUNNING OF THE ORGANISATION BY CONSUMERS</strong></td>
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<td>The organisation is run entirely by consumers, who decide whether or not to involve other people in decision making.</td>
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