

'HAVING YOUR SAY'

**SELF-ADVOCACY AND INDIVIDUALS EXPERIENCING
MENTAL ILL-HEALTH**

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SETTING THE SCENE

1.1. Defining Self-advocacy

Self-advocacy is often described as 'speaking up for oneself' (Wertheimer, 1993). However, it has been interpreted and defined in various ways. For example, in a booklet by Dawson & Palmer (1993), individuals with learning difficulties stated what they considered self-advocacy to be. The statements included 'thinking for yourself', 'making decisions', 'being confident and assertive', 'changing negative first impressions', and 'having the right to make mistakes and have a go'.

Although self-advocacy can vary in meaning between individuals, a number of definitions of self-advocacy has been suggested. Crawley (1988) considers self-advocacy to be:

'the art of making choices and decisions and bringing about desired change for oneself'.

Croft & Beresford (1993) define self-advocacy as:

'people speaking and acting for themselves and asserting their own rights, both as individuals and in groups with shared experiences or beliefs.'

Wertheimer (1993) states that self-advocacy is something which most people do without giving it much thought. However, due to a number of reasons, some individuals may experience difficulties in asserting their own rights. For example, some individuals who experience mental ill-health may not be accustomed to, or find it difficult to put forward their own views and opinions. This

may be due to experiences in the past where they felt they were not listened to or that their views were devalued. The development of self-advocacy within the mental health field may be an important way for such individuals to begin to bring their own concerns to light and to exert more control over their own lives. This may involve individuals speaking out on basic everyday decisions, such as, what time they get up in the morning, what they wear, what time they eat, who they spend the day with, to wider issues, for example, speaking out on the right to clear, detailed information about their mental illness, having the choice of alternative treatments, and advocating for equality in housing and employment.

1.2. History of Self-advocacy

Recent years have seen a growing interest in the self-advocacy movement within various fields. This research report addresses self-advocacy within the mental health field. Although self-advocacy has received increasing attention, it is not something entirely new, as its origins can be traced back to a number of roots.

Firstly, the self-advocacy movement is often associated with groups which were set up to speak out against the psychiatric system (Campbell, 1990). As far back as the 1620's and 1860's groups, such as 'The Petition of the Poor Distracted People in the House of Bedlam', and 'The Alleged Lunatics Friend Society' spoke out against the psychiatric system of the day (GPMH, 1986). The 1960's

and 70's introduced groups such as 'People not Psychiatry' and 'British Networks for Alternatives to Psychiatry'. These groups were commonly referred to as 'anti-psychiatric' (Campbell, 1990) and were associated with psychiatrists like Ronald Laing, Thomas Szasz and David Cooper. The first patient-only groups were set up in the 1970's, for example, the 'Mental Patients Union' and 'Protection of the Rights of Mental Patients' (PROMPT). Within and outside these groups people began to speak out against a psychiatric system which they viewed as oppressive and to advocate changes on their own behalf. Although the growth of the self-advocacy movement may in part be attributed to the work of such initiatives, self-advocacy and the anti-psychiatric movement are not totally synonymous. Self-advocacy is not restricted to individuals speaking out against the psychiatric system, but can have a wider agenda.

The self-advocacy movement was also partly influenced by the rise in consumerism. The initiation of the consumerism movement is traced back to the work of Ralph Nadar and his published account of the irresponsibility of the American car industry in 1965 (Barker & Peck, 1987). The consumerism movement challenged organizations to listen to the views of their consumers and to develop services in line with their needs and wants. Subsequently, new structures and procedures emerged which provided opportunities for consumers to speak out about the products and

services they received. Consumerism extended from the high street stores into health and social services with the result that there was a 'growing fashion for consumerism within the NHS' (Campbell, 1990).

The development of consumerism within the mental health field sought to provide further opportunities for individuals on the receiving end of mental health services to speak out about the services they received. The term 'user involvement' or 'user participation' has been given to this process of individuals being given, and taking the opportunities to become involved in mental health services.

1.3. User Involvement Vs Self-advocacy

Within much of the literature reviewed, the terms mentioned above, such as, self-advocacy, consumerism and user involvement have often been employed interchangeably. Although each of the terms relate to individuals speaking out, they are not synonymous.

As already stated, self-advocacy concerns individuals having their say on a wide range of issues affecting their lives, for example, where they live or activities they are involved in during the day. User involvement and user participation specifically refer to individuals speaking out and becoming involved in mental health services. Therefore, user involvement is only one part of self-advocacy.

However, the process of involving users in mental health services has received much attention. Articles such as, 'Towards User Power' (Lindow, 1991), 'User involvement: Policy into Action' (Pfluger, 1992) and 'How to involve users and carers' (NSF, 1992) offer guidelines and suggestions for providing individuals with the opportunity to speak out about mental health services.

This emphasis on encouraging individuals to speak out about mental health services was facilitated by the introduction of a growing body of government policy which encouraged service providers to take into consideration the views of service users. For example, the White Paper: 'Caring for People' (Dept. of Health, 1989) proposed that the views of individuals and their carers should be taken into account. Also, the proposal in 'People First', originated in the Griffith Report (1988) stated that:

'people receiving help will have a greater say in what is done to help them, and a wider choice'.

1.4. User Involvement

Although recent years have seen a growing interest in user involvement within mental health services, a lot of confusion surrounds the term and what it means. As Beresford (1992) states:

'User involvement is full of ambiguities, contradictions and inconsistencies. It is a very confused and confusing area.'

The confusion is partly a result of user involvement being used as an umbrella term for referring to the process of involving individuals in mental health services. For example, some organizations may regard user involvement as having one service user representative on a planning committee, whereas, for another organization it may be interpreted as a group of individuals playing an active role in running their own services. However, in each case the term user involvement is often applied. To help clarify the meaning of user involvement, two important distinctions can be drawn, differentiating between:

- the **purpose** of involving users in services
- the **level** to which they are involved.

Purpose of Involvement

Barnes & Wistow (1992) identify two main purposes of involving users in services.

i) To **improve the quality of services** by making them more sensitive or responsive to the needs and preferences of individuals who use them.

ii) To **extend the capacity of users** to participate in decisions about the design, management and review of services.
(emphasis added)

Although these two approaches differ in the purposes they seek to achieve, Barnes &

Wistow (1992) state that they should not necessarily be regarded as completely separate. They suggest that the initial involvement of individuals in mental health services as a means of sensitising services to the needs of users may result in longer term consequences of increasing user empowerment.

Croft & Beresford (1993) draw a similar distinction in involving users in services. They identify two approaches towards user involvement:

- 'consumerism' or 'supermarket' approach
- 'democratic' or 'empowerment' approach

Croft & Beresford (1993) state that the consumerism approach towards user involvement is primarily concerned with involving users as a means of improving the efficiency, economy, and effectiveness of services. In contrast, they suggest that central to the democratic approach is the empowerment of individuals. It is concerned with individuals having more say in all areas of their lives, not solely in the services they receive. (This model is very similar to what has been stated about self-advocacy. Para 1.3).

Levels of Involvement

Individuals experiencing mental ill-health can be involved in mental health services to varying degrees. Beresford & Croft (1993) have differentiated between three levels of involving users in services; information

gathering, consultation, and direct involvement.

The first level of user involvement, 'information gathering', involves service users giving service providers feedback about how they benefit from existing mental health services and suggesting ways in which such services could be improved. As such, information gathering is a one way process where service users '*inform change*'.

Further up the ladder of user involvement, Beresford & Croft (1993) introduce the process of 'consultation'. Consultation can range from an informal meeting between a service user and provider to discuss some aspect of the service they are receiving, to a more formal meeting between elected service user representatives and service providers to discuss proposals for future mental health services. Consultation is a more interactive process than information gathering. It aims to provide users with a greater level of input into the process of changing and developing services and '*influence change*'.

Although information gathering and consultation have been recognized as important components for encouraging users to be involved in the services they receive, Beresford & Croft (1993) suggest that the process cannot end there. Otherwise, they state, the situation would be one of:

'us giving them our information and them telling us their decision'

Beresford & Croft point out that only when the suggestions and ideas offered by service users are translated into action can users be said to have a direct involvement in the decision making process and be involved in '*deciding change*'.

The final stage of service users participating in mental health services involves service users '*making their own change*', by developing and running their own organizations and services.

1.5. Individuals V's Groups

Speaking out and having a say, both within and outside mental health services, can occur at two levels; at an individual and/or at a group level. Some individuals may wish to speak out on their own, expressing their own views and voicing particular concerns. For example, an individual may file a complaint about some aspect of a service he/she receives, or request more information about his/her care from the professionals they are in contact with. Group or 'collective' self-advocacy involves individuals coming together to give voice to common concerns. However, the two are not mutually exclusive.

A number of distinctions can be drawn between groups which are generally referred to as 'self-advocacy' groups. Firstly, Simons (1992) refers to the distinction between groups which are set up and run 'by' group members and those which are set up and run 'for' group members. However, this distinction can

become somewhat blurred as some groups run 'by' group members may receive support and advice from mental health workers or independent 'allies'. Also, groups initiated and run 'for' individuals by mental health workers may receive various degrees of input from service users. A survey by Crawley (1988) found that a typical group based in a day centre for individuals with learning difficulties received input from 8-12 elected service users.

Self-advocacy groups operate at both a local and a national level. National self-advocacy groups include, Voices (set up by the National Schizophrenic Fellowship), Survivors Speak Out, and United Kingdom Advocacy Network (UKAN).

1.6. Difficulties Encountered

Although various groups and initiatives have emerged which provide opportunities for service users to speak out for themselves, the development of self-advocacy into the mental health field presents many challenges. Difficulties may be encountered when individuals are afforded and take these opportunities to speak out for themselves. Problems can arise for individuals who use mental health services and individuals who work in them. As stated by Parker et al. (1989):

'user empowerment is an unsettling process which challenges and threatens workers and users alike'.

Service Users

It is unrealistic to assume that the development of new opportunities for individuals experiencing mental ill-health to speak out for themselves will automatically result in service users advocating on their own behalf. For many individuals the prompts, 'you decide', 'what do you think?', or 'have your say', will be insufficient for them to speak out on their own. Mental health organizations may need to address some practical considerations, such as providing information and offering training and support, to enable some individuals to make the change from being spoken for to one of speaking out for themselves. As a manager of a day centre stated:

'We learnt that the 'over to you folks' strategy cannot work. We know that we have to provide the structures, the bedrock of security which might enable users to take some control' (Tyson, 1987).

Structures and support within mental health organizations are required to ensure that the views of individuals who use the services do not go unheard. Without sufficient support a situation could arise where the views of individuals who are more confident and articulate take precedence over the views and opinions of individuals who are less confident in speaking out for themselves. It is important that individuals who are less verbal are supported in appropriate ways to enable them to voice their views. Some individuals may require an advocate to ensure that their voice will be heard.

Eliciting the views of individuals through more formal procedures, such as, group discussions, questionnaires and/or one-to-one interviewing can present some difficulties. Those involved in obtaining the views of users need to ensure that the questions being asked are relevant to the individuals concerned, and that the responses given reflect individuals' genuine opinions and not those which they feel the researcher/staff member wants to hear. A number of such problems were encountered during the 'Having Your Say' project and will be discussed in greater detail during the report.

Mental Health Workers

The introduction of self-advocacy may also present challenges for staff and managers of mental health services. It has been suggested that there is a delicate balance between supporting individuals to do things on their own and doing things for them, between speaking for them and affording them opportunities to speak for themselves (Petch, 1992). Staff may also have to deal with an increased number of complaints and criticism of services which may result if users take the opportunity to have their say. Campbell (1989) identified three attitudes staff can hold towards self-advocacy; open hostility, apathy or support. However, within the literature reviewed there appeared to be a lack of information addressing in greater detail the attitudes staff hold towards individuals speaking out for themselves. This project aims to explore in greater detail the issues and

implications for staff if service users are further encouraged to speak out for themselves.

1.7. 'Having Your Say' Project

This project aims to bring together the views of Praxis service users and staff concerning self-advocacy. It aims to use this information to suggest ways in which individuals experiencing mental ill-health can be further encouraged to speak out and have their say both within and outside mental health services.

ABOUT THE RESEARCH PROJECT

2.1. Management of the Project

A working group was set up to advise on the direction of the research project and to monitor its progress. The group comprised of three individuals living in Praxis accommodation and three members of Praxis staff (Deputy Director, Senior Research Officer, Research Officer). The working group met at various stages throughout the duration of the project to discuss any arising problems and to determine ways in which the project could be taken forward.

An initial task identified by the working group was to rename the self-advocacy project. The group members felt that the term 'self-advocacy' would hold little meaning for many of the individuals taking part in the study and decided to adopt a more 'catchy', user-friendly title. The working group came up with the title '*Having Your Say*'. The group also felt it was important to have a working definition of 'having your say', and defined it as:

'the art of making choices and decisions and speaking up for yourself to bring about change'.

2.2. Aims of the Project

The 'Having Your Say' project aimed to explore:

- individuals' feelings about what encouraged them to speak out for themselves

- individuals' feelings about what prevented them from speaking out for themselves
- the issues and implications for Praxis staff regarding service users 'having their say'
- ways in which Praxis could further encourage and support individuals to speak out for themselves.

2.3. Overall Plan

The 'Having Your Say' project was conducted in three main stages. The first stage of the study involved setting up focus groups as an exploratory method to obtain information for the design of an interview schedule, which was to be used to elicit service users views. The focus groups were made up of Praxis service users. The second stage was concerned with interviewing Praxis service users, using the interview schedule, to explore in greater detail many of the issues raised by participants during the focus groups. The final stage of the project aimed to explore the issues and implications for Praxis staff regarding service users speaking out for themselves. Focus groups, made up of Praxis staff, were conducted to elicit staff views.

2.4. Stage I: Service User Focus Groups

A focus group has been described as:

'A carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment'. (Kreugar, 1994).

A focus group is a special type of group in terms of its size, composition and purpose. A group is typically composed of 6 to 10 individuals, but can range from as few as 4 to as many as 12 (Kreugar, 1994). A key principle in forming a focus group is homogeneity (Kingry et al., 1990). Participants of a focus group normally share some characteristic in common which is determined by the purpose of the study, for example, users of a particular product or service, or individuals who work in a specific field. A series of focus groups can be conducted to detect trends and patterns across groups.

Focus groups emerged in the late 1930's when they were used primarily within the field of market research. However, more recently they have been used in social science and health research (Kingry et al., 1990).

Focus groups can be used as an exploratory method to inform the main study by providing information about the topic being investigated. For example, Elbeck & Fecteau (1990) employed focus groups to find out which aspects of services were regarded as important by service users. This information was then used in the design of a service user satisfaction questionnaire.

In the 'Having Your Say' study, focus groups were used to obtain information regarding self-advocacy from individuals using Praxis services. This information was used as a basis for designing an interview schedule.

Using focus groups as a preliminary to the main study offered many advantages. One advantage was the insight the groups provided into the terminology individuals used when referring to self-advocacy. Such terminology could then be incorporated into the interview schedule. Conducting focus groups as a preliminary to constructing the interview schedule also ensured that issues important to Praxis service users were highlighted for inclusion in the interview schedule.

2.4.1. Participants

In order to obtain a wide range of views and opinions regarding self-advocacy, four Praxis accommodation and support schemes were selected to be involved in the focus groups. The four schemes varied on a range of dimensions. One scheme provided accommodation and support to an older, mainly female group of individuals and another scheme was comprised primarily of a younger male group. The other two schemes provided accommodation and support to a range of individuals. Three different accommodation and support models were represented in the focus groups, Dispersed Intensively Supported Housing (DISH), Flat

Cluster (FC) and Residential Care Home (RCH)¹.

Permission to conduct the focus groups within the four schemes was obtained from scheme managers. All service users residing in the four accommodation schemes were sent information about the nature of focus groups and what participation would involve. Scheme managers assisted in the process of explaining the study to service users and finding out who wished to participate.

2.4.2. Procedure A topic guide format (Kreugar, 1994) was used to facilitate discussion during the focus groups. A series of topic areas were identified through discussion with the working group and a review of the literature on this area. The topic areas were introduced during the focus groups as a means of stimulating discussion between the participants.

To support a 'permissive and non-threatening environment' (Kreugar, 1994) in which individuals would feel comfortable sharing their views and opinions, an outside facilitator was used to conduct the focus groups. The

group facilitator was made aware of the objectives of the research project and the role of the focus groups in the study. The researcher attended the group sessions to provide assistance to the group facilitator.

At the beginning of the focus group sessions each member of the group was asked to introduce him/herself to the other group members. Every attempt was made to create a relaxed atmosphere.

Permission was obtained to record the group discussions, with the knowledge that all information would remain strictly confidential. To supplement the tape recordings of the group discussions, detailed notes were taken throughout. Each focus group lasted approximately one hour.

The taped discussions were fully transcribed and a content analysis of each focus group was carried out. Key words and phrases were identified and response categories created. Categories were clustered together to identify recurring themes. This information was used as the basis for drawing up an interview schedule.

During the focus groups some individuals took the opportunity to 'have their say' about various quality issues within their accommodation and support scheme. An interim report was written addressing these issues.

¹ **DISH:** Individuals live in houses dispersed throughout an area. The scheme offers a range of support to facilitate appropriate degrees of independence.

FC: Consists of single person flats grouped together with communal facilities. Staff are based on site, for part of the day, and provide a range of support.

RCH: Residents have their own 'bedsitting' room and share communal facilities. 24 hour staff support is provided.

2.5. Stage II: Interview Schedule

Based on the information obtained from the focus groups and on a review of the literature, an interview schedule was drawn up.

Careful attention was given to the wording and phrasing of questions in order to avoid ambiguities and the use of jargon. The interview schedule included a range of closed, open-ended, and Likert-scale questions. Visual response cards were used to facilitate responses to the Likert-scale questions.

The interview schedule comprised of four main sections:

- Tenants / Residents² Meetings
- Complaints Procedure
- Praxis Review Meetings
- General

• Tenants / Residents Meeting

Some of the Praxis accommodation and support schemes hold tenants/residents meetings. The aim of these meetings, involving both service users and staff, is to provide an opportunity for individuals to raise issues of concern. The interview schedule asked individuals who attended tenants meetings if they were satisfied with how often these meetings were held. Individuals were asked to rate how much they spoke out at these meetings and what things prevented them from speaking out.

² Residents are those individuals living in Praxis Residential Care Homes. Tenants are all other individuals using Praxis accommodation and support services.

Individuals were asked to rate how helpful they found the meetings in enabling them to 'have their say', and to suggest ways in which they felt the meetings could be improved.

Participants involved in Praxis accommodation schemes which did not hold tenants/residents meetings were asked if they would like this type of meeting to be held in their scheme.

Within some accommodation schemes, tenants/ residents socialize with each other. The schedule asked individuals if they felt getting together with other users in this way helped them to speak out for themselves and 'have their say'.

• Complaints Procedure

Praxis operates a formal complaints procedure which aims to enable individuals to make a complaint about any aspect of the service with which they are dissatisfied. The interview schedule asked individuals if they knew whether Praxis had a complaints procedure in operation and how they found out about making a complaint. Individuals were also asked about what they felt prevented them from making a complaint about the service they received, and how easy or difficult they would find it to make complaints about various issues. Participants who had made a formal complaint in Praxis within the past year were asked to rate how satisfied they were with the way their complaint was dealt with, and if they felt the complaints procedure

helped them to 'have their say'. Individuals were asked if, and in what ways, they thought the complaints procedure in Praxis could be improved.

- **Praxis Review Meetings**

Praxis review meetings aim to provide individuals using Praxis services with an opportunity to voice their views and opinions about the service they receive and to determine if they are receiving the kind of service they require. Due to specifications in service agreements, Praxis review meetings often involve a number of people, including, the tenant/resident, Praxis key worker, Praxis manager, Praxis assistant director, social worker, C.P.N, co-ordinator of the Community Mental Health Team, consultant psychiatrist and/or a general practitioner. Attendance at review meetings can range from approximately four to eight persons. The schedule asked individuals who had attended a review meeting, how much they spoke out during their review meeting, and what things prevented them from speaking out. Individuals were asked if they thought the review meetings 'belonged' to them, and how much they felt the review meetings helped them to 'have their say'.

- **General**

The final section of the interview schedule addressed general issues surrounding the whole area of self-advocacy. Individuals were asked if they felt Praxis staff listened to them and in what ways they thought staff

encouraged /discouraged them to speak out for themselves. It addressed the issue of confidentiality, and included questions about service users speaking up in relation to issues other than Praxis services. Individuals were asked to identify ways in which they felt Praxis could further support them to speak out for themselves.

2.5.1. Participants

To explore the issues surrounding self-advocacy for individuals experiencing mental ill-health, service users from nine Praxis accommodation schemes were included in the project. These included individuals using a range of accommodation and support services: DISH (Dispersed Intensively Supported Housing), FC (Flat Cluster), RFC (Residential Flat Cluster)³ and RCH (Residential Care Home). Two Praxis schemes were not included in the project, as one scheme had recently been evaluated and the other scheme was soon to be evaluated. This was to prevent tenants being overloaded with research.

2.5.2. Procedure

During the initial stages of the project, when the focus groups were being carried out, a 'Having Your Say' poster was designed and displayed in each accommodation and support scheme. The poster aimed to make individuals using Praxis services aware that the project was taking place and to provide

³ **RFC:** Consists of single person flats grouped together with communal facilities. 24 hr staff support is provided.

them with some general information about the study.

When the interviews were ready to commence, all individuals were asked by their scheme manager if they would like to receive further material about the project. Those individuals who said they would like to receive more information were sent a 'Having Your Say' information leaflet. The leaflet provided more detailed information about the nature of the project, confidentiality issues and what participation would involve.

A small scale pilot study was carried out to assess the interview schedule. A number of minor alterations were made to the schedule based on the comments from some individuals involved in the pilot study.

Written consent was obtained from service users who wished to participate and individual interviews were arranged. The majority of the interviews were conducted within individuals homes. However, for practical reasons, a few interviews were conducted in a Praxis office. The interviews lasted approximately one hour.

A content analysis of responses to the open-ended questions was carried out and response categories set up. To increase reliability, another researcher independently coded a sample of the questionnaires. Comparison and cross-checking of the response categories resulted in a high level of agreement between the two researchers. Where disagreement

occurred, the response categories were re-examined and necessary changes made.

2.6. Stage III: Staff Focus Groups

Focus groups were used as a means of exploring the issues and implications for Praxis staff regarding service users speaking out for themselves. To facilitate group homogeneity, (Kreugar, 1994) two types of focus groups were set up; those for scheme managers and grade III staff to attend and those for grade II and grade I staff⁴.

2.6.1. Participants

All members of Praxis staff working in the accommodation and support schemes, excluding administrative staff and relief workers, were included in the project. Staff were sent a letter inviting them to participate in the focus groups. The letter explained the aims of the project and what participation would involve.

Staff members were asked to liaise with their scheme manager if they wished to participate in the focus groups to ensure that proper cover for their scheme could be arranged.

2.6.2. Procedure

The topic areas to be introduced during the staff focus groups were identified through the literature available, information from the

⁴ Scheme managers and grade III staff hold relevant qualifications. Grade II and grade I members of staff are unqualified with appropriate experience at different levels.

service user focus groups and discussion with some members of staff. The topic areas were used to facilitate discussion during the group sessions. To encourage staff to discuss their views and opinions openly surrounding service user self-advocacy, an outside facilitator was brought in to conduct the focus groups. Verbal consent was obtained to record the group discussion.

The researcher also took detailed notes throughout the group sessions. Each group lasted approximately 60-90 minutes. The focus groups were fully transcribed and key words and phrases noted. Codes were generated and attached to the transcripts. Over-riding themes were identified.

KEY FINDINGS

3.1. Service User Focus Groups

Forty-four individuals using four Praxis accommodation and support services were invited to participate in the focus groups. Eighteen individuals agreed to take part, nine males and nine females. A focus group was set up for each of the schemes. The groups ranged in size from 3-6 individuals. Focus groups with a small number of participants are called 'mini-focus groups' (Kreugar, 1994). The small group size potentially provides more opportunity for participants to share their opinions and ideas, but presents the drawback of having a smaller total number of views and experiences being shared.

During the service user focus groups, participants raised a number of issues surrounding self-advocacy. Service users highlighted the role staff played in encouraging them to speak out for themselves. Service users mentioned how much they valued staff being available for them to talk to and taking time to listen to what they had to say. Individuals, who were living in accommodation schemes which held tenants/residents meetings, discussed what normally happened during the tenants meetings. Some individuals stated the benefits of attending Praxis social activities and meeting up socially with other users from their schemes. A number of participants raised issues regarding the complaints procedure in Praxis. Individuals discussed who they would go to with a complaint and what they would do if they had a complaint against a member

of Praxis staff. Service users mentioned a number of factors involved in preventing them from speaking out and making a complaint. These included, not wanting to be seen as complaining all the time and lack of confidence.

The information obtained from the service user focus groups, together with the available literature, was used as a basis for drawing up an interview schedule.

3.2. Staff Focus Groups

57 members of Praxis staff were sent a letter explaining the study and what taking part in a focus group would involve. Thirteen individuals participated in the focus groups, eight scheme managers and grade III staff (4 males, 4 females) and five grade II and I staff members (1 male, 4 females). Three mini-focus groups were set up, involving 3-5 individuals. Areas of overlap between the staff focus groups and findings from the tenants interview schedule will be discussed together. Additional issues raised by staff will be discussed at the end of the section on key findings.

3.3. Interview Schedule

102 individuals from nine Praxis accommodation and support schemes were approached for this study. 87 individuals stated they would like to receive an information leaflet about the study. 37% (n=38) of service users who were approached for the study agreed to participate and

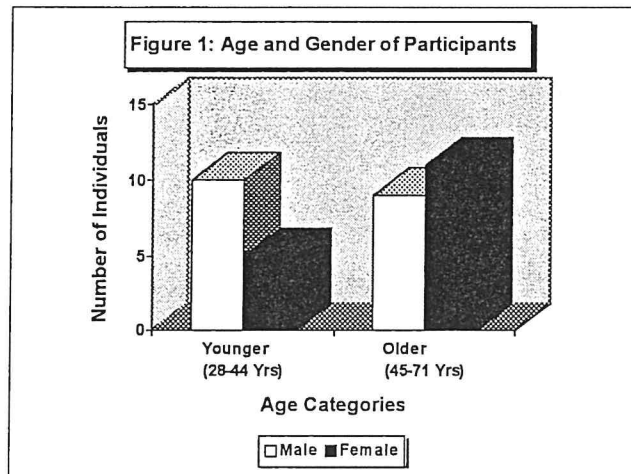
individual interviews were arranged. Three of the interviews provided limited information as the interviewer experienced difficulties in communicating the questions to the service users in an understandable manner. These interviews were excluded at the analysis stage of the project. One individual asked to discontinue the interview approximately half-way through. The information given up to this point is included in the findings.

Of the 35 completed interviews, 19 were male and 16 were female. As a percentage of the total number of service users approached for the study, 30% of males and 39% of females participated in the study. Participants had a mean age of 44 years (range 28-71 years). This is fairly representative of service users who were approached for the study, as they had a mean age of 45 years (range 23-88 years). There was no significant age difference between males and females who were approached for the study. However, an independent t-test indicated a significant difference in age between males and females who participated in the study ($p=0.027$), with males having a mean age of 41 years ($s.d.=7.9$) and females a higher mean age of 48 years ($s.d.=13.3$). For the purpose of looking further at the age differences between

male and female participants, two age categories were created, 'younger' (28-44 years) and 'older' (45-71 years). These categories were based on the overall mean and range of ages of participants. Twice as many 'younger' males ($n=10$) as 'younger' females ($n=5$) participated in the study (Figure 1).

There were more than double the number of females in the 'older' age bracket ($n=11$) than in the 'younger' age group ($n=5$).

Service users who took part in the study were using a range of Praxis accommodation and support services (Table 1). Individuals were using the services for a mean period of 22 months (range 3-60 months).



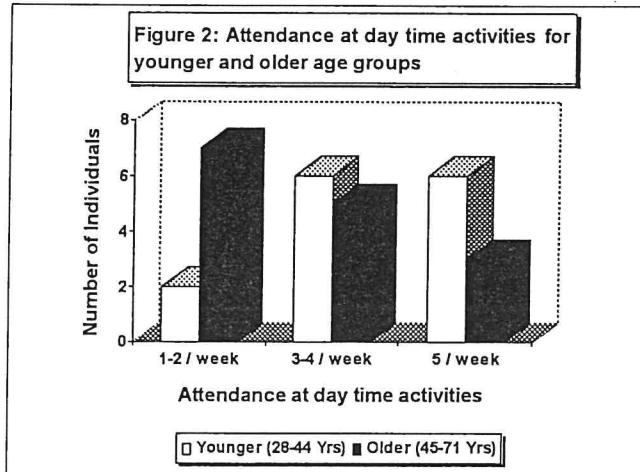
Service	Percentage	Number of Participants (n)
FC	34%	(n=12)
DISH	29%	(n=10)
RCH	29%	(n=10)
RFC	9%	(n=3)

As a percentage of the total number of service users approached for the study, 56% of individuals living in Praxis Residential Care Homes participated in the study. 36% of individuals using Flat Cluster services and 25% of individuals living in DISH accommodation and support schemes took part

in the study. 20% of service users living in Residential Flat Cluster schemes participated in the study.

attendance at daytime activities than older individuals.

The majority of participants (89%, n=31) attended some kind of day-time activity. 42% (n=13) attended Industrial Therapy Organization and 39% (n=12)



In looking at the gender breakdown for attendance at daytime activities, 39% (n=7) of male participants attended daytime activities everyday, whereas only 15% (n=2) of

attended a local day centre. 13% (n=4) of individuals were involved in 'other' daytime activities, which included assisting in a local Patients' Council, doing voluntary work, attending a drop-in centre and a family caring centre. 6% (n=2) of participants were in employment.

females attended activities daily. The majority of females (46%, n=6) attended daytime activities 1-2 times per week.

Figure 2 displays the breakdown of attendance at daytime activities for the younger and older participants. Almost half of the individuals in the older age group (47%, n=7) attended daytime activities once or twice a week. 20% (n=3) of older individuals attended activities every day. In contrast, the majority of individuals in the younger age group (86%, n=12) attended daytime activities everyday or 3-4 times per week with only 14% (n=2) attending activities once or twice a week.

3.4. Tenants Meetings

80% (n=28) of individuals interviewed were living in a scheme which held tenants meetings. Of those who did not have tenants meetings, 11% (n=4) said they would like to have tenants meetings in their scheme and 9% (n=3) were unsure.

Tenants meetings were well attended, with the majority of participants (61%, n=17) stating they attended 'all' tenants meetings and almost a third (32%, n=9) attending 'some' meetings. Only 7% (n=2) reported that they 'rarely' attended tenants meetings.

It is perhaps not surprising that younger individuals would have a higher level of

For those schemes which held tenants meetings, the frequency with which meetings were held varied (Table 2, overleaf).

Weekly	39%	(n=11)
Fortnightly	21%	(n=6)
Monthly	29%	(n=8)
Irregular	11%	(n=3)

The majority of participants (61%, n=17) using Praxis services which held tenants meetings, felt the frequency with which meetings were held was 'about right'. Almost a third of service users (32%, n=9) who attended tenants meetings stated they would prefer to have fewer meetings in their scheme. For those schemes which held tenants meetings, a lack of purpose was the main reason put forward for wanting fewer meetings.

Although service users stated that the meetings provided them with an opportunity to bring up any complaints, discuss social events and be informed about activities going on within their accommodation scheme, some individuals felt tenants meetings lacked purpose. For example, one individual who attended tenants meetings every fortnight said '*not much happens at them*' and felt that having the meetings once a month would be sufficient.

3.4.1. Speaking Out at Tenants Meetings

The majority of service users (74%, n=20) said they would speak out at least sometimes during tenants meetings. 37% (n=10) stated they would '*often*' speak out and the same percentage said they would '*sometimes*' speak

out. About a quarter of individuals (26%, n=7) said they would '*never*' speak out at tenants meetings.

74% (n=20) of participants who attended tenants meetings felt that if they had something they wished to say, the meetings were helpful in providing a platform for getting their views put forward. Some service users suggested a number of ways in which they found the meetings helpful. These fell into three main categories.

- **Opportunity to Speak Out**

Seven individuals referred to the opportunity, or platform which tenants meetings provided them to speak out.

'It provides a good opportunity to have your say'

'I say my piece at these meetings'

'It's a time when you can bring anything up'

'You can speak out if you want about things'

- **Opportunity to Raise Complaints**

Five individuals specifically mentioned having the opportunity to bring up any problems or complaints during tenants meetings.

'Bring up problems at the meetings'

'If I have any complaints I can bring them up'

'Say about anything wrong in the flat'

• **Socialization**

Some individuals (n=5) felt that the meetings were helpful as they provided an opportunity to meet with other service users from their scheme and to mix with members of staff.

'Get to meet other tenants....hear their problems'

'Good to have managers and tenants together'

'Opportunity when everyone is together'

'Staff sit on and chat at the end of the meeting, good to mix with them'

From the views expressed by some of the staff during the focus groups, there were areas of concern in relation to tenants meetings. Staff mentioned problems in encouraging service users to attend the meetings. During tenants meetings there were difficulties experienced by staff in encouraging service users to put forward their views and opinions. Staff also mentioned that it was often the same few individuals who spoke up during the meetings. As a result, staff felt that they often received a narrow view of what service users felt about various issues.

'It is very difficult in tenants meetings to get them to air their views'.

'Most of them didn't turn up and of those who did, the people didn't speak up and the staff did most of the talking'.

'I find that at tenants meetings, a lot of them are very quiet...you would have one or two who would speak, the rest are just very silent and wouldn't say much, just agree with whatever is said'

Some members of staff felt that the problem of encouraging service users to speak out at tenants meetings may partly be attributed to the social setting of tenants meetings. Staff suggested that tenants meetings could be less formal, that they could be held in places other than the Praxis office and could be combined with other social events within the scheme. Staff suggested that implementing these changes might create an atmosphere more conducive to service users expressing their views and opinions.

3.4.2. Factors Preventing Service Users from Speaking Out at Tenants Meetings

Service users were asked to rate on a 4-point Likert scale how much various factors would prevent them from speaking out at tenants meetings. At the analysis stage, the four categories 'would always stop me', 'would sometimes stop me', 'would rarely stop me' and 'would never stop me', were collapsed into two categories 'would stop me' and 'would not stop me'.

Feeling unwell in relation to their mental health and not feeling confident enough were the two main difficulties individuals felt prevented them from speaking out at the meetings. 63% (n=17) of service users stated

feeling unwell in relation to their mental health would prevent them from speaking out at tenants meetings. The same percentage said not feeling confident enough would prevent them from 'having their say' at the meetings. Rather than speaking out during tenants meetings, some individuals stated they would prefer to speak to staff members individually. For example, one individual said:

'I feel better talking on a one-to-one basis rather than in a big group'

Staff also emphasized the importance of one-to-one relationships between tenants/residents and staff. Staff felt that some service users within their schemes would be more comfortable speaking to a staff member alone than in a large group. Staff also felt that they often had a better chance of finding out what was on an individual's mind when speaking to him/her on their own.

'Whatever is on their mind may come out...but it would be better on a one-to-one basis, rather than in a group.'

'At the end of the day it is down to the relationship between

them and their keyworker... and if they have something to say, even the shyest ones, they will say if something is wrong.'

'At an individual level you can get further'.

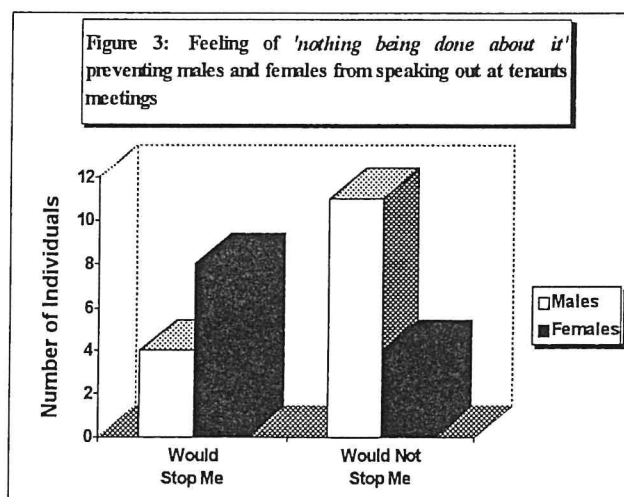
Staff highlighted the importance of visiting tenants in their own homes, building up a rapport with service users and obtaining their trust and confidence as a means of encouraging individuals to speak out.

A chi-squared analysis was used to examine gender differences in the extent to which various factors prevented service users from speaking out at tenants meetings. The analysis indicated a significant difference between males and females in speaking out with regard to the feeling of 'nothing being done about it' ($X^2 = 4.3$; $p=0.038$). More females, 67% ($n=8$) than males, 33% ($n=4$) said this feeling would prevent them from speaking out at tenants meetings (Figure 3). Given the age difference between the two genders, age may be a confounding variable.

There were no gender differences on the other factors.

Some individuals ($n=4$) who were positive about tenants meetings also raised areas of concern. These included service

users not knowing in advance what the meetings were going to be about, and only a few individuals putting forward their views



and opinions at the meetings. One individual felt that some service users were not aware that they could have their say at tenants meetings. Another individual felt there was not much to talk about at tenants meetings.

3.4.3. Improving Tenants Meetings

26% (n=9) of service users felt tenants meetings in their scheme could be improved. Suggestions for improvement fell into four main categories:

- **Improved Content of Meetings (n=3)**

'It is the same thing every fortnight...a bit of variety would be good'

'There is little to talk about'

- **Having Fewer Meetings (n=2)**

One individual using a Praxis service which held tenants meetings fortnightly said:

'Once every two weeks is a bit much'

Another individual from a scheme which held weekly tenants meetings stated:

'Once a fortnight would be enough'

- **Better Attendance (n=2)**

'More tenants getting along to the meetings'

- **Other (n=2)**

'Too cramped and not enough seats, but it is the biggest room'

'Some staff make it easier than others. It depends which staff are there'

Service users were asked about other opportunities they had to meet with tenants/residents where they lived. Less than half of the participants (40%, n=14) met up socially with other individuals from their accommodation and support scheme. Of those who did meet up with other service users, the majority (n=11) felt it helped them to speak out for themselves. The main benefit of meeting with other tenants was 'social' reasons. One individual stated:

'I have never had so many friends in my life'

Other benefits of meeting with other service users included talking to individuals who were in similar circumstances, keeping up to date with what was going on in their scheme and gaining practical support from the other tenants. Of those who did not meet up with other tenants / residents (n=21), the majority (76%, n=16) expressed no wish to socialize with other service users from their scheme.

3.5. Complaints Procedure

Less than half of the service users interviewed, (49%, n=17) were aware that Praxis had a procedure for making a complaint. A quarter (n=9) said they were not aware that Praxis had a complaints procedure, and a quarter of participants (n=9) said they were not sure. Of those individuals who did know about the procedure, having it explained by a member of staff and receiving written information were

the two main ways in which they found out about making a complaint in Praxis.

About half of the participants (51%, n=18) identified their scheme manager as the person they would go to if they had a complaint to make. Almost a third of participants (31%, n=11) said they would go to a Praxis worker.

Service users were asked to rate on a 4-point scale how easy or difficult they would find it to make certain complaints. For analysis purposes, the four categories 'very easy', 'quite easy', 'quite difficult' and 'very

difficult' were collapsed into two categories 'easy' and 'difficult'. The majority of individuals (63%, n=22) said they would find it difficult to make a complaint about a member of Praxis staff (Figure 4). 64% (n=21) of

service users said they would find it difficult to complain about their scheme manager, (two individuals did not answer this question as they could not imagine wanting to make a complaint against their scheme manager). 51% (n=18) of service users said they would find it difficult to make a complaint against a mental health professional. 52% (n=17) of individuals said they would find it difficult to complain about another Praxis tenant/resident,

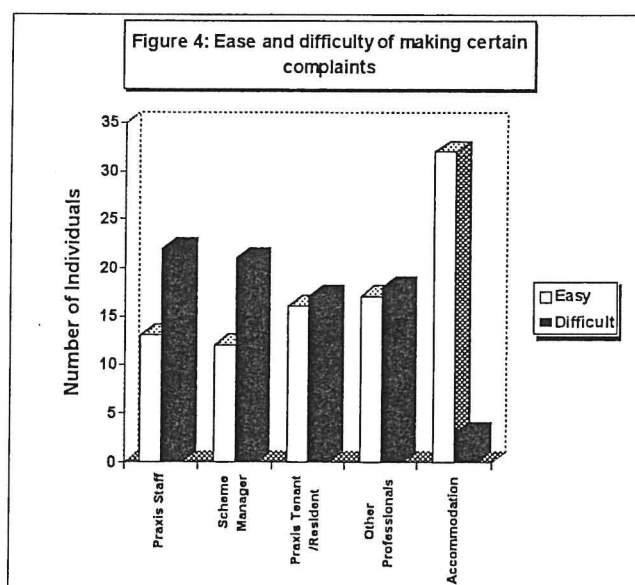
(two individuals did not answer this question as they had no contact with other service users from their scheme). In contrast, 91% (n=32) said they would find it easy to make a complaint about their accommodation.

3.5.1. Factors Preventing Service Users from Making a Complaint

15% (n=5) of service users stated they had made a complaint in Praxis within the past year. All but one of the individuals were satisfied with the way their complaint had

been dealt with. This individual was not satisfied because he/she felt there was a long gap between the time the complaint was made and the outcome.

Not wanting to be seen as causing trouble was the most important



factor in preventing service users from making a complaint in Praxis. 70% (n=23) of service users said this feeling of 'not wanting to be seen as a troublemaker' would prevent them from making a complaint.

Staff also felt that the fear of being seen as a troublemaker may be a factor in preventing service users from making complaints. Staff

suggested that service users might feel that if they did speak out there would be some kind of backlash from staff, or that their status and security within the organization would be threatened. This is summed up by one member of staff who said:

'I think they (tenants) feel protected by Praxis to a degree and so they are reluctant to kick against Praxis itself. They might feel threatened and vulnerable if they were to say within Praxis "I don't like..", they might feel their status within the organization was being threatened'

Staff felt that they had an important role to play in encouraging service users to speak out and bring up any complaints. It was felt that within the organization there was a training need for some members of staff in the complaints procedure. One member of staff said:

'That is a training need within Praxis. It is a real understanding of the complaints policy we need, not for someone to read it and understand the procedure, but understanding the reason why there is a complaints policy and why managers have to investigate'

65% (n=22) of service users said lack of confidence would prevent them from making a complaint about the service they were receiving from Praxis. Feeling unwell, in relation to their mental health, was also an

important factor preventing 62% (n=21) of service users from making a complaint.

3.5.3. Improving Complaints Procedure

Almost half of the participants (46%, n=15) felt that the procedure for making complaints in Praxis could be improved. Of these service users, six were aware of the current complaints procedure in Praxis and nine individuals were not aware, or did not know of the procedure. Some individuals suggested ways in which they felt it could be improved. These fell into three main categories.

• Information (n=8)

The majority of service users (67%, n=6) who were not aware of the complaints procedure in Praxis stated they would like to receive more information about the process of making a complaint.

'Give information about the procedure of making complaints'

'More information about making a complaint. I wouldn't know what to do if I had a complaint'

Two individuals who were aware of the complaints procedure also felt that it could be improved by having more information about making a complaint.

From the whole sample, less than half of the service users (40%, n=14) said that staff at their scheme explained to them what to do if

they wanted to make a complaint. A quarter of individuals (n=9) said they did not receive an information leaflet explaining the complaints procedure and almost a third of service users (32%, n=11) could not remember whether or not they had received an information leaflet. Some individuals stated that when they came into the accommodation and support scheme they received a lot of written material and could not remember if one was about making a complaint. For example, one service user said:

'you get a lot of leaflets about things'

A few suggestions were made concerning the way in which this information about making a complaint in Praxis could be provided. One individual suggested that once every six months staff should go over the procedure with service users, refreshing them on how to make a complaint. Another individual suggested that the complaints procedure should be explained to service users after they had been living in the accommodation scheme for a period of time, not prior to moving to the scheme, when there were a lot of other things happening.

This was also raised by staff during the focus groups. One member of staff questioned the way in which service users were currently given information about making a complaint. It was felt that explaining the procedure to tenants/residents when they had just arrived into the scheme was possibly not the most appropriate time.

- **Structure of Complaint Procedure (n=3)**

One service user, who was not aware of the complaints procedure in Praxis, suggested that a formal panel system would be beneficial, where those individuals involved in the complaint would have an opportunity to speak to the panel individually and then be brought together.

Two individuals, who knew about the complaints procedure, also felt the structure of the procedure could be improved.

'It would be better if you didn't have to go to your scheme manager. If you could go above that person and go to someone outside of the accommodation scheme'

'Have a complaints box'

- **End Result (n=2)**

One individual, who was not aware of the complaints procedure, felt that service users should have no fear of being contradicted if they made a complaint. Another individual, who had made a complaint in Praxis, felt the procedure could be improved if action followed the complaint being made. The individual had made a complaint 4-5 months prior to taking part in the research project and at the time of being interviewed stated the complaint had not yet been dealt with.

3.6. Praxis Review Meetings

69% (n=24) of participants had previously attended a Praxis review meeting. Two

individuals did not attend their previous review meeting(s). Four individuals were unsure if they had attended a review in the past and four individuals had not been using Praxis services long enough to have been involved in a review meeting. The individual who asked to discontinue his/her interview did not complete the section on review meetings.

For those individuals who had attended review meetings, the majority (83%, n=20) were satisfied with the frequency of meetings. 42% (n=10) of participants who attended reviews did not feel that the meetings 'belonged' to them. Some service users suggested ways in which they felt the meetings were not their meetings. Four individuals felt the reviews were mainly for the professionals attending the meetings to have their say, rather than for service users to speak out. For example, one individual said:

'The professionals have all the say'.

Five individuals who did not feel the meetings belonged to them, referred to the lack of control they felt they had over the meetings. One individual said:

'If it was my meeting I would be chairing it'.

Three individuals felt that review meetings had a two-way purpose, that they were for service users to speak out and also were for the benefit of professionals who attended the meetings.

3.6.1. Preparation for Review Meetings

Participants were asked about practices and procedures within Praxis which aim to prepare service users to speak out at review meetings.

- **Meeting with Praxis Staff**

Of the 24 individuals who had attended a review meeting, 38% (n=9) said they had met up with a member of Praxis staff prior to the meeting to help prepare them for their review. Over half of the individuals (58%, n=14) stated they had not met up with a member of Praxis staff before their review meeting and one individual was unsure. The majority of service users (n=11) who had not previously met up with a Praxis worker felt this would be helpful.

- **Support Plan Checklist⁵**

77% (n=17) of service users had not gone through a Support Plan Checklist with a Praxis worker before their review meeting. The majority (n=11) said they would find it helpful to use such a checklist in preparation for their review. However, of the 18% (n=4) who had used a Support Plan Checklist, only one service user said they found it helpful. Information was not obtained from two individuals.

⁵ Individual Support Plans are drawn up between the service-user, scheme manager and referral agent. They are based on service-users' needs in relation to their day to day living requirements. A Support Plan Checklist acts as a preparation guide for staff and service-users to ensure all components of the Individual Support Plan are addressed prior to attending a review meeting.

• Staff Speaking on Service Users Behalf

The majority of service users (71%, n=17) were not aware that they could ask a staff member to speak on their behalf at a review meeting. Eleven individuals thought this would be helpful. Six individuals did not think staff speaking for them would help in having their views put forward.

Knowing Agenda Beforehand

Over three-quarters of service users (79%, n=19) said they had not known beforehand what would be discussed at their review meeting. The majority (n=12) felt that it would be helpful to be aware of what was going to be discussed at the meeting. Of those individuals who had been in the situation where they had known about the agenda beforehand (n=5), all but one found this a helpful practice.

3.6.2. Factors Preventing Service Users from Speaking Out at Review Meetings

Service users were asked to rate on a 4-point scale the extent to which certain factors would prevent them from speaking out at their review meeting. The 4 categories, 'would always stop me', 'would sometimes stop me', 'would rarely stop me' and 'would never stop me', were collapsed into the

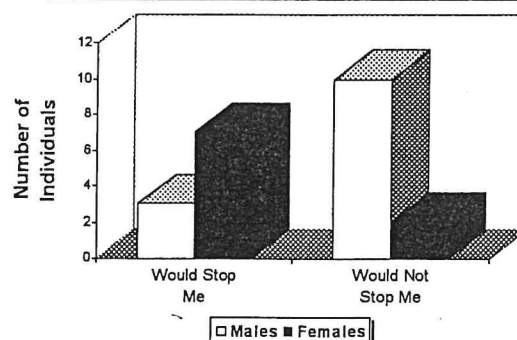
two categories 'would stop me' and 'would not stop me'. 68% (n=15) of participants said lack of confidence would prevent them from speaking out at their review meeting. Also, over half of the individuals (59%, n=13) said 'not wanting to be seen as a troublemaker' and 'feeling unwell', in relation to their mental health, would prevent them from speaking out at their reviews.

A chi-squared analysis was conducted to examine whether gender differences played a role in preventing service users from speaking out at reviews. The analysis indicated a significant difference between males and females in speaking out at reviews for fear of 'not being listened to' ($X^2=6.4$; $p=0.011$). More females (70%) than males (30%) said this feeling of 'not being listened to' would prevent them from speaking out at their review meeting (Figure 5). However, age could be a confounding variable.

3.6.3. Improving Review Meetings

Half of the individuals (n=12) who had attended a review meeting felt the meetings could be improved. The main way in which service users felt they could be improved concerned the membership of review meetings.

Figure 5: Feelings of 'not being listened to' preventing males and females from speaking out at review meetings



• **Fewer Professionals**

Five service users stated that they would prefer to have fewer mental health professionals attending their review meetings.

'Too many professionals there, would rather have less professionals'

'Fewer people there would make me less nervous. Go in and there are 8-10 people around the table..only 3-4 wouldn't make me feel so bad'

'Can be too many authority figures'

• **Individuals Present/Absent**

Seven service users mentioned individuals who they said they would like to be present at their review meetings, and individuals who attended that they did not wish to be there.

'Only people you know well'

'Would like day centre staff to be there'

'Praxis staff should not always be present'

'People from organizations you have left should not always be there. Not always good for keyworker to be there'

'At the beginning of the meeting, should just be myself, Praxis worker, social worker and Praxis manager, and then bring in the Assistant Director and the psychiatrist'

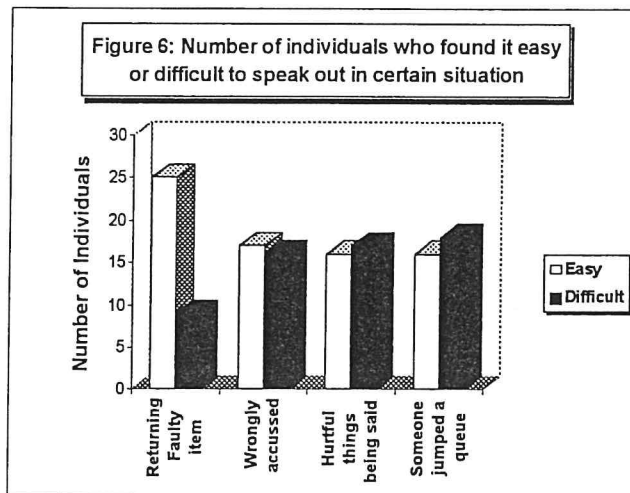
3.7. Confidentiality

The majority of individuals interviewed (88%, n=30) felt that staff in Praxis listened to them. Almost three quarters (74%, n=25) felt that Praxis staff treated what was said to them as confidential. 18% (n=6) of individuals did not feel that staff kept information to themselves. Three individuals felt that staff members chatted amongst themselves, although one individual said he/she did not think this included personal things. One participant did not feel information was confidential as he/she said tenants heard about other tenants through staff members. One individual stated that what was said to a member of staff was carried into the office and to the scheme manager and another individual felt that sometimes staff members were in a position where they could not keep information confidential, for example, thoughts about suicide.

3.8. General

Tenants were asked to rate on a 4-point scale how easy or difficult they would find it to speak out in certain situations outside the accommodation setting. At the analysis stage, the four categories 'very easy', 'quite easy', 'quite difficult' and 'very difficult' were collapsed into two categories, 'easy' and 'difficult'. The majority of service users (74%, n=25) said they would find it easy to return a faulty item (Figure 6). Slightly more than half (52%, n=17) said they would find it easy to speak out if someone wrongly made an accusation towards them. 52% (n=17) said

they would find it difficult to speak out if someone said hurtful things to them and 53% (n=18) said they would find it difficult to say something to someone who jumped a queue in front of them.



'Staff encourage me to go out and mix..this helps me to speak out'

• **Praxis Activities**

Some service users (n=7) referred to various activities within Praxis

which encouraged them to speak out. The activities mentioned included tenants/residents meetings, social evenings, assertiveness training courses, first aid course and Quality Development Group⁶ meetings.

3.8.1. Encouraged to Speak Out

The majority of service users (85%, n=29) felt that Praxis encouraged them to speak out for themselves. Some individuals suggested ways in which they felt encouraged to speak out. These fell into three main categories.

• **Praxis Staff**

Thirteen individuals mentioned the role Praxis staff played in encouraging them to speak out for themselves.

'Staff keep asking at residents meetings if there is anything you would like to say'

'Workers have time to have a conversation with me and ask me how I am keeping'

The fact that staff are there and you can talk to them...Praxis takes time to listen'

'Scheme manager and staff encourage you to speak out'

• **'Having Your Say' Project**

Five individuals mentioned the 'having your say' project as a way in which they were encouraged to speak out for themselves.

'Yes, otherwise they wouldn't have you coming. Scheme manager is letting us have our say even though he knows we will probably say things against the scheme'

'Having the focus groups educated me about speaking out'

⁶ The aim of the Quality Development Group is to consider ways in which the quality of Praxis services can be improved. The group is comprised of service-users, volunteers and staff.

3.8.2. Factors which help Service Users to Speak out for Themselves

Beyond the organisational related issues mentioned above, the kind of things service users mentioned which they felt helped them to speak out for themselves were grouped into four categories.

- **Personal Well-being**

9 individuals referred to their personal well-being as an important factor in enabling them to speak out for themselves. For some service users (n=5) feeling in a good mood and being confident helped them to have their say.

'Feeling well'

'Being calm and thinking sensibly'

'Confidence, happiness and being in a good mood'

For other individuals (n=4), feeling angry or being upset about something helped them to speak up for themselves.

'If I was angry or upset I would speak out'

'If I am angry and see things that are unfair I would have to speak out'

- **Relationships with other people**

Eight individuals mentioned the importance of having a good relationship with the people they are speaking to.

'Knowing you can trust people...being sure you know the other person and how they will react'

'Feeling comfortable with people. Knowing people helps me to speak out'

'Knowing people will be receptive to what I am saying'

- **Knowledge**

Some individuals (n=5) referred to the need to know they were 'right' before they would be able to speak out. One individual said:

'If I know enough about what I am talking about I will speak out'

- **Actively Encouraged/Supported**

Five individuals mentioned being supported or encouraged to speak out as important factors. This included being supported by members of Praxis staff and also family members and friends.

'If I thought I would be listened to I would speak out more'

'Encouragement of the workers to speak out'

- **Other Factors**

Five individuals referred to other factors which they felt encouraged them to speak up for themselves. These included being in a pleasant atmosphere and the knowledge that there will be action following what has been said.

3.8.3. Factors preventing Service Users from Speaking Out for Themselves

Service users mentioned a number of factors which they felt prevented them from speaking out for themselves.

• **Outcome of Speaking Out**

Eleven individuals mentioned factors related to the outcome or consequences of speaking out. The statements included the fear of people not liking you, afraid of hurting peoples' feelings, not wanting to get people into trouble, not being taken seriously and nothing being done about it.

'Generally people not liking you'

'Afraid of hurting peoples' feelings'

'People not believing what you say'

• **Personal Well-being**

Some individuals (n=8) stated that if they were in a bad mood they wouldn't speak out but would 'bottle it up' inside. For one individual, listening to voices and thoughts inside his/her head prevented him/her from speaking out. Another individual said if he/she felt scared inside he/she would not speak out.

• **Lack of Confidence**

Not feeling confident was an important factor in preventing service users from speaking out in general (n=6). This also prevented many

individuals from having their say both within tenants meetings and review meetings.

3.8.4. Staff Focus Groups

In general, within the staff focus groups staff were positive about service users speaking out for themselves. Some of the comments from staff included:

'I think it is very good. It is only right.'

'It could only improve services for everybody.'

'I think it gives them a sense of empowerment and control as well.'

Staff also mentioned some areas of concern which they felt could arise if individuals within Praxis accommodation and support schemes were further encouraged to speak out for themselves. They highlighted a number of implications service user self-advocacy could have for staff members and for the wider organization.

• **Manipulation**

Staff suggested that if individuals using Praxis services were further encouraged to speak out for themselves, some quieter tenants could be manipulated by more vocal, assertive service users. Staff felt that a situation could arise where the views of individuals who were more confident in speaking out would take precedence over the views of quieter, less

vocal tenants. For example, one staff member stated:

'you would have one ring leader, one or maybe two dominant residents taking over and steamrolling everybody else.'

There was also a concern amongst staff that some staff members could feel manipulated by more vocal service users. Staff were concerned that some individuals using Praxis services would begin to complain about *'everything and everybody'* and that complaints would be made about members of staff, which would not be based on legitimate reasons. Staff also felt that some service users would try to play staff members off against each other and one member of staff stated that some service users would try to get *'staff to jump through hoops'*.

Some members of staff highlighted the importance of having a cohesive staff team within the accommodation schemes as a way of minimizing the potential for service users to manipulate members of staff. One individual suggested it would be important for individual staff members to work together as part of a team and for service users to receive a consistent approach from staff.

- **Feelings of Frustration**

Within the staff focus groups, some individuals mentioned feelings of frustration when they came across situations where service users did not participate in making

choices and decisions. The example was given of organizing social activities within the accommodation and support schemes. Some staff members who tried to encourage service users to play an active role in suggesting and organizing social activities felt frustrated when service users did not participate in this process and were happy to leave it to staff to organize. This situation often presented staff with the dilemma of either continuing to organize the social activities for service users or leave it up to the individuals themselves, in which case staff felt it would be likely that social activities would not be organized. Neither of these two options sat comfortably with some staff members and often led to feelings of frustration.

- **Tenants Right Not to Speak Out**

Within the focus groups, staff suggested that it would not be a priority for some individuals using Praxis services to speak out for themselves. Staff stated that for such individuals staff had to respect their *'right to silence'*. They were also aware of the role they played in ensuring that such individuals did not feel under pressure from more vocal service users to be actively involved in self-advocacy.

- **Conflict**

It was recognized by staff involved in the focus groups, that the views of staff and service users often differ. For example, staff stated that service users' views of what they feel would be best for them, often conflicts

with the views held by Praxis staff and other mental health professionals. Staff felt that if service users were further encouraged to speak out and express their own opinions, this conflict of views would become more evident.

- **Staff Role**

Staff felt that if service user self-advocacy was further promoted within the organization this could lead to changes in staff roles. Some of the changes mentioned by staff included:

'no longer organizing, but overseeing'

'demanding higher levels of skill'

'playing the role of an advocate'

Staff also mentioned that if service users began to speak out more for themselves this could lead to an increased workload for staff. One member of staff summed this up by stating:

'the more responsive you are to peoples' choices the more accommodating you have to be, the harder you have to work'.

Some members of staff felt that already within their accommodation scheme they were very flexible to the needs of service users and that it was difficult to envisage how this could be improved.

- **Praxis Policies**

Staff mentioned a number of ways in which increased service user self-advocacy could impact on the organization as a whole. Staff suggested that it could result in changes to Praxis policies, with new policies further taking into consideration the views of service users.

Staff felt the development of service user self-advocacy could have an impact on the current practice of staff selection. Some staff suggested that if users were further encouraged to speak out and exert more influence over decisions affecting their lives, they should have a say in the process of appointing staff who would be working in their accommodation scheme.

In supporting the idea of service users playing an active role in the process of staff recruitment, one member of staff referred to the issue of representation. He/she mentioned the problem of ensuring that an individual on an interview selection panel would be representative of other tenants and would not be *'ploughing their own furrow'*.

Staff also suggested that individuals using Praxis residential services, could become involved in the selection process of residents being accepted into the scheme.

- **Staff Training and Support**

Staff within the focus groups emphasized the role of training for staff members. It was felt that if service users were to be further encouraged to speak out and advocate on their own behalf, staff would require training in certain areas.

For example, one member of staff said:

'It is going to identify a lot of areas in terms of skills deficits in the staff..it's going to identify a lot of training needs for staff in terms of providing the clients with an effective service which is geared towards empowerment.'

Although staff within the focus groups highlighted the importance of staff receiving additional training, staff also noted that it was difficult setting time aside to train staff.

Staff also felt there would be a greater need for staff support. Staff suggested that opportunities to receive peer support within the organization would need to be identified.

DISCUSSION AND RECOMMENDATIONS

4.1. Overview

The 'Having Your Say' Project raised a number of important issues for both service users and staff regarding service user self-advocacy. In discussing the findings from the project it must be kept in mind that these were the views of a small proportion of individuals using Praxis services and staff working within the accommodation and support schemes.

The working group defined 'having your say' as:

'the art of making choices and decisions and speaking up for yourself to bring about change'.

User involvement is specifically concerned with individuals speaking out and being involved in the mental health services they receive. This project addressed issues in both of these areas. It obtained suggestions from service users as to how they felt they could be further encouraged to have their say in relation to the service they received and also wider issues in their lives.

Based on the findings of the project, the working group made a number of recommendations. Many of the recommendations are specifically concerned with improving practices and procedures within Praxis as a means of encouraging users to speak out more for themselves. For example, suggestions are made for improving the format of tenants meetings, providing more information about the complaints

procedure and developing practices which aim to prepare service users to speak out more for themselves at their review meetings. In addition, some of the recommendations address wider, more general issues surrounding service users having their say. For example, findings from the project identified the need to explore ways of promoting service user self-confidence.

The project highlighted a number of important areas for future research. For example, although much has been written about the need to provide service users with information, such as making a complaint, little has been written about the timing at which information should be provided. Also, staff members stated that they felt the development of service user self-advocacy would raise a number of training needs for staff. These were not identified through the research project and may require further consideration by scheme managers in conjunction with the training department.

4.2. Tenants / Residents Meetings

On the whole, tenants meetings were well attended with the majority of service users stating they attended all meetings. Also, the majority of service users were satisfied with the frequency with which tenants meetings were held in their schemes. Some service users highlighted the benefit the meetings provided in terms of meeting socially with Praxis staff and other tenants / residents from their scheme.

Three quarters of service users said that if they had something in particular they wished to say, tenants meetings provided a platform for getting their views across. However, only a third of service users said they would regularly contribute their opinions and ideas to the group meetings. This suggests that if service users had issues they wanted to raise, or if they had a suggestion to make, tenants meetings provided a useful venue for doing so. However, service users felt that often at tenants meetings there was not much to talk about and they felt the meetings lacked purpose. This is summed up by one individual who said 'not much happens at them'. A lack of purpose in tenants meetings was the main reason put forward by those service users who wanted fewer tenants meetings within their accommodation and support schemes.

Staff mentioned difficulties in encouraging service users to put forward their views and opinions during tenants meetings. Staff felt this may partly be attributed to the social setting of tenants meetings and suggested that if the meetings were less formal or held in conjunction with other social events, a more enabling atmosphere could be created for service users to 'have their say'.

- **Recommendations**

4.2.1. *Tenants meetings can have a number of advantages, for example, providing a platform for service users to speak out and promoting the development of social*

relationships within the accommodation schemes. Where service users wish to have tenants meetings, these should be set up or continued. (Para. 3.4.1.)

4.2.2. *Where tenants meetings take place within the accommodation schemes, it is important that they have a clearly defined purpose. This should be shared by service users and staff. (Para. 3.4.)*

4.2.3. *Service users and staff should be aware that tenants meetings do not have to follow one particular format. They should be actively encouraged to introduce new ideas for encouraging service users to speak out during tenants meetings. One suggestion the working group came up with was having the meetings over a relaxed meal.*

4.2.4. *Where tenants meetings are not found to be the best method for passing on information within accommodation schemes, staff and service users should be encouraged to put forward different ways of exchanging information. For example, rather than call a tenants meeting to pass on a few small bits of information, where it is appropriate, service users could be sent or given a letter instead. A suggestion sheet could be put on a noticeboard as a way of obtaining ideas for social outings or a suggestion box could be made available. This may not increase the extent to which service users put forward their views and opinions, but it may prevent*

feelings of frustration associated with attending meetings which seem to have little purpose. (Para. 3.4.)

4.3. One-to-One Relationships

Findings from the project underlined the importance of one-to-one relationships between service users and staff as a means of encouraging users to 'have their say'. Some service users stated they felt most comfortable speaking to staff on an individual level rather than within a large group. Also, staff thought they often had a better chance of finding out what was on an individual's mind when speaking to service users on their own.

Although staff's work with tenants on a one-to-one basis may not be as visible as group activities, its value should not be underestimated. Good one-to-one communication between service users and staff needs to be recognized and promoted as an important way of encouraging service users to assert their views.

- **Recommendation**

4.3.1. *Staff need to be continually reminded, through supervision and training, of the important role they play in encouraging service users to speak out for themselves. Particularly given the increasing promotion of user groups, the value of less immediately visible one-to-one work needs to be promoted at a wider level. (Para. 3.4.2.)*

4.4. Complaints Procedure

Less than half of the service users who took part in the study were aware of the complaints procedure in Praxis. Service users stated they would like to receive more information about the process of making a complaint. All service users must receive information on how to make a complaint about the service they receive from Praxis. Also, an appropriate mechanism must be used to ensure this information has been passed on to service users.

It was encouraging that almost all of the service users stated they would find it easy to make a complaint about any aspect of their accommodation they were not satisfied with. However, approximately half of the service users said they would find it difficult to make a complaint against the scheme manager, other members of Praxis staff, other service users and other mental health professionals.

It is perhaps not surprising that more service users stated they would find it difficult to make a complaint against another individual compared to some aspect of their accommodation. Making a complaint about a faulty light switch, while it may be difficult, is not as difficult as making a complaint against another individual.

The main factor preventing service users from making a complaint was the fear of being seen as a troublemaker. Staff also felt this would prevent service users from making a

complaint. Staff felt that service users might feel that if they did make a complaint, their status within the organization might be threatened. This highlights the importance of creating a climate in which individuals feel they can complain about any aspect of the service with which they are dissatisfied.

- **Recommendations**

4.4.1. *Almost a third of service users stated that they could not remember whether or not they had received an information leaflet explaining the complaints procedure. The organization needs to identify other ways in which they can promote, on an ongoing basis, the complaints procedure to service users. For example, displaying a poster on a noticeboard in a common room or Praxis office and/or having someone from Praxis coming into the schemes each year explaining the procedure to service users. (Para. 3.5.3.)*

4.4.2. *As well as service users having the information necessary to make a complaint in Praxis, it is important that within the accommodation and support schemes there is a climate/atmosphere in which service users feel they can complain about any part of the service they are not satisfied with. (Para. 3.5.1.)*

4.5. Information

Some service users highlighted the importance of knowing enough about what they were speaking out about, or 'knowing they were right' as an important factor in encouraging

them to 'have their say'. For individuals experiencing mental ill-health to be able to make informed decisions and speak out on their own, it is important that they are provided with information covering a range of topics.

The Health of the Nation, Key Area Handbook (1994) identified six areas where service users may require information: Rights, Services, Treatment and Medication, Complaints, Mental Health Act (1983), and Self-help Groups/ Community Networks.

Much literature addresses the need for services to provide service users with information which is relevant, up to date and understandable. One suggestion to ensure that information meets the needs of users is to involve service users in the planning of information leaflets, posters, and other methods of communication. As stated in a booklet by Age Concern, addressing the needs of older people within Northern Ireland:

'Users of services need to be given opportunities to question the way in which information is provided and to influence the content, presentation and delivery of that information'.

Findings from the project also raised an important issue regarding the timing of when information should be provided. With regard to the complaints procedure, service users and staff suggested the information should be explained to service users after they had been

living in the scheme for a period of time, not prior to moving, when many changes are taking place and there is a lot of information to take in.

Although there is a lot of resource material highlighting the need to provide clear, detailed information, little has been written about the timing of when information should be provided. This is an important factor which requires further examination.

- **Recommendations**

4.5.1. *It is important that individuals using Praxis services are given information which is clear, understandable and in a suitable format. The working group have suggested that a Tenants Handbook should be drawn up to include information which service users may need from the time they first come into the accommodation scheme, including information on how to make a complaint in Praxis. This piece of work is currently being taken forward by the Quality Development Group within Praxis.*

4.5.2. *In addition to providing service users with information, it is necessary to identify the best time for information to be provided. (Para. 3.5.3.)*

4.6. Praxis Review Meetings

The majority of service users who had previously attended a Praxis review were satisfied with the frequency of review meetings. Some service users were unsure of

the aim of review meetings, a common misunderstanding being that service users felt that they were being assessed. Many of the service users felt that the reviews were for the professionals who attended, rather than for them to speak out and 'have their say'. This was summed up by one individual who stated: *'the professionals have all the say'*.

Some individuals indicated concern over the membership of their review meetings. They felt that there were too many mental health professionals present and stated they would prefer fewer people attending. Also, service users mentioned people who attended their reviews whom they did not wish to be present and suggested other people whom they would like to attend their reviews.

The majority of service users were not aware of the practices and procedures within Praxis which aim to prepare service users to put forward their views at review meetings. It is important that practices, such as service users meeting up with their keyworker prior to their review, and tenants knowing the agenda of the review beforehand, are highlighted within Praxis. Also, that new ways are identified to encourage individuals to have their say at review meetings.

- **Recommendations**

4.6.1. *Service users need to have clear information about the aim of Praxis review meetings. It is not the individual who is being assessed. It is the service provided by*

Praxis that is being assessed. This needs to be reinforced by the style in which review meetings are carried out. (Para. 3.6.)

4.6.2. *Service users should be given a say in who they would like to be present at their review meeting. Because review meetings usually have an input from professionals outside Praxis, Praxis alone cannot decide who should or should not attend. However, Praxis staff should assist service users in voicing their opinions about who they would like to have present at their review meetings. Where it is not possible to meet the requests of service users about who attends their reviews, they should be given an explanation as to why other individuals need to be present. (Para. 3.6.3.)*

4.6.3. *The majority of service users were not aware of the different practices and procedures within Praxis which aim to prepare service users to speak out at their review meetings. One possible way for service users to feel more prepared for their reviews would be to meet up with their Praxis keyworker and/or scheme manager before their review. At this meeting service users could work through a number of set questions with the staff member(s). These questions could then be asked at their review meeting. Useful areas to cover would be:*

Accommodation: (e.g. Are there any parts of your accommodation which you feel could be improved?)

Daytime Activities: (e.g. Are there other kinds of activities you would like to be involved in during the day?)

Support Received: (e.g. How do you feel about the support you receive from Praxis staff?)

Personal Change: (e.g. Have you noticed any changes in yourself since using the Praxis accommodation and support service?)

4.6.4. *The majority of service users were not aware that staff could speak on their behalf at their review meeting. At this preliminary meeting between the service user, Praxis keyworker and/or scheme manager, service users could be asked whether or not they wished to attend their review meeting, or if they would prefer staff to speak on their behalf. (Para. 3.6.1.)*

4.6.5. *As part of the procedure for review meetings, service users should be asked by their project worker how they felt about the way in which the meeting was conducted. Any areas service users are not satisfied with, or ways they felt the meeting could be improved, should be noted. These changes should be taken into consideration before their next review meeting.*

4.7. Self-Confidence and Skills

Lack of confidence was an important factor in preventing service users from speaking out for themselves.

It has been suggested within the self-advocacy literature, that for individuals to begin to speak out more for themselves, training may be required in two main areas, that of promoting self-confidence, and learning / relearning skills. As stated by Bell (1987):

‘Effective self-advocacy entails the recovery of confidence and skills which psychiatric labelling and treatment erode’.

Individuals may require training in various social skills and/or assertiveness skills to enable them to begin to speak out more on their own. Also, some individuals experiencing mental ill-health may wish to take part in the running of a self-advocacy group and may require training in practical skills. For example, training in skills such as chairing a meeting, taking minutes or managing group finances.

Crawley et al. (1988) have suggested that feeling good about yourself and developing skills are closely related. Crawley states, that as an individual begins to believe in him/herself and feels more confident, he/she will be more capable of learning and exercising new skills, which in turn, may promote higher levels of self-confidence.

- **Recommendation**

4.7.1. *Ways need to be explored to promote service user self-confidence. This may involve offering formal training in social / confidence skills, developing social activities*

and/or long term one-to-one work between service users and staff. (Para. 3.4.2., 3.5.1., 3.6.2.)

4.8. Other Issues Related to Service Users Speaking Out

The majority of service users felt that Praxis encouraged them to speak out for themselves. Some service users mentioned social activities organized within Praxis which they felt encouraged them to speak out for themselves. Service users also highlighted the role Praxis staff played in encouraging them to ‘have their say’. The majority of service users felt staff listened to them and treated what was said to them as confidential. This reflects good practice within the accommodation and support schemes which should be maintained.

- **Recommendations**

4.8.1. *It was clear that service users valued social outings and training courses. It is important that these are further developed within the accommodation and support schemes. (Para. 3.8.1.)*

4.8.2. *Some service users were concerned about confidentiality in general and the passing on of information between staff. Confidentiality must be maintained at all times. Where information needs to be passed on to other members of staff, this must be made clear to service users. (Para. 3.7.)*

4.9. Gender Differences

More females than males said that feelings of 'nothing being done about it' would prevent them from speaking out at tenants meetings. Also, compared to males, more females stated that feelings of 'not being listened to' would prevent them from speaking out at review meetings.

- **Recommendation**

4.9.1. *Given the number of service users who took part in the research project, it is difficult to draw general conclusions from the findings regarding gender differences. At this stage, it would be important that staff are aware that it may be an issue, so that future information may be gathered.*

4.10. Other Issues for Staff

On the whole, staff were very positive about the idea of service user self-advocacy. However, they raised a number of areas of concern which they felt could arise if service users were further encouraged to speak out for themselves. For example, staff mentioned the potential for manipulation of staff members by more vocal, assertive service users and the potential for conflicting views between staff and service users becoming more evident.

Staff also felt that the development of self-advocacy amongst service users could lead to changes in staff roles and consequently training needs amongst staff. In particular, staff mentioned the need for some members of staff to receive training in the complaints

procedure. They felt it was important for staff to have an understanding of why the complaints procedure was important and to recognize the rights of tenants to make complaints about any aspect of the service with which they are not satisfied. However, scheme managers noted that it was difficult to set aside time to train staff.

- **Recommendations**

4.10.1. *The current procedure for training staff members in the complaints procedure needs to be reassessed and, if necessary, developed to ensure staff have an understanding of the complaints procedure. (Para. 3.5.1.)*

4.10.2. *Specific training needs for staff need to be identified in order to deal effectively with the changes which could come about if users begin to speak out more for themselves. (Para. 3.8.4.)*

4.11. Representation

The issue of representation was raised in a staff focus group concerning service users being involved in the process of recruiting staff within their accommodation and support scheme. One member of staff questioned how staff could be sure that a service user selected to sit on the selection panel would represent the views of other tenants and not simply represent his/her own interests.

Beresford & Croft (1993) state that the issue of representation is one of the most raised

arguments against the involvement of individuals in mental health services. Often individuals experiencing mental ill-health who speak out and advocate changes are considered to be the 'more able minority'. Subsequently, their views are not considered to represent the views of the rest of individuals experiencing mental ill-health. Service user representation has been regarded as a catch-22 situation (Simons, 1992). If individuals experiencing mental ill-health do not speak out they do not have any say, yet, if they do voice an opinion it is often not acted upon because it is regarded as 'unrepresentative'.

- **Recommendation**

4.11.1. *The issue of service user representation is one which would need further exploration if user involvement is to be developed at this level.*

4.12. Tenants Right Not to Speak Out

Staff noted that for some individuals using Praxis services, speaking out more for themselves would not necessarily be a priority for them. Therefore, although changes to organizational practices can be made and further steps be taken to develop service user self-confidence, for some individuals this may not necessarily result in them speaking out more for themselves. For individuals who do not regard it as a priority to speak out, their right to silence needs to be respected. It is also important, however, to explore why service users prefer to remain silent about

their views. This would involve exploration of support individuals may require.

For service users who find it difficult to assert their own views and opinions, some members of staff suggested that they may require the work of an advocate to speak on their behalf.

- **Recommendation**

4.12.1. *Providing advocacy support for individuals using Praxis services should be further explored.*

4.13. Where Do We Go From Here?

The 'Having Your Say' project raised a number of important issues and concerns that service users had about speaking out for themselves. However, this is only the starting point. It is important that the project does not end here.

- **Recommendations**

It is necessary that the recommendations made by the working group are taken forward by the appropriate sections of the organization. Also, that the implementation of the recommendations is part of a formal monitoring process. Many of the issues raised by tenants and staff may be relevant to other mental health organizations and it is important that this information is made available to them.

- **Research**

Findings from the 'Having Your Say' Project identified a number of areas for future research:

Many service users said they did not feel confident enough speaking out for themselves. Further research is needed to explore the best ways of encouraging the development of service user self-confidence.

The need to provide service users with information to enable them to make informed decisions have been widely recognized. However, little has been written about the timing at which information should be provided and the form it should take. This is an important area which needs to be explored.

Some members of Praxis staff stated that if service users were further encouraged to speak out more for themselves, staff would need training in certain areas. It is necessary that specific training needs for staff are identified and ways suggested as to how these could be met. It will also be important to determine how this training impacts on how staff deal with self-advocacy issues.

The majority of the findings from the 'Having Your Say' Project were concerned with practices and procedures within Praxis which encourage or prevent service users from speaking out for themselves. For example, the complaints procedure, tenants meetings and review meetings. It is important that further research is carried out to take a closer look at the factors that help and prevent service users from asserting their views in situations outside of mental health services.

4.14. Conclusion

In many respects, this project raised more questions regarding service user self-advocacy than it answered. However, one thing that was clear from the project was that for individuals to be further encouraged to have their say, individuality is paramount. What will work for one individual may not be the same for everyone. Therefore, staff play a pivotal role in recognizing and implementing the best methods for encouraging service users to 'have their say'.

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