Letting Through Light: Ealing Service User's Audit

October 2003

Contents

Introduction		1
Recommendations from service users		5
Key Challenges for Ealing services from the Audit		6
1.1	Basic information about the sample of people	9
1.2	Ethnicity	10
1.3	Language	11
1.4	Religion	11
2.1	Quality of Life & Mental Distress	12
2.2	Confidence building	13
2.3	Relationships	13
3.1	Early Contact with Mental Health Services	14
3.2	Feelings on First Contact	15
3.3	Describing distress	16
3.4	First Contact with Ealing Services	17
4.1	Getting help	18
4.2	CPA	20
5.1	Treatments for Mental Distress	20
5.2	Side Effects	21

6.1	Contact with Police	23
7.1	Stay in Hospital	24
7.2	Experience of the Ward	25
7.3	Safety on the ward	25
7.4	Relationships with Hospital Staff	27
7.5	Activities on the Ward	28
7.6	Spirituality in Hospital	28
7.7	Freedom to go out	29
7.8	Food on the ward	29
7.9	Hospital	30
8.	Confidentiality	30
9.1	Family	31
9.2	Parenthood	32
10.	Solidarity	33
11.	Culture	34
12.	System vs. People	34
13.	Power games	35
14.	Personal Experience of Racism	36
15.	Stereotyping	36
16.1	Day Centre & Residential Experience	37

16.2 Name badges 38

16.3 Spirituality in Centres 39

16.4 Activities at Centres 40

17.1 Information 41

17.2 Information about benefits overall 42

18. Job stress 43

19. Physical health 44

20. Hopes for the Future 45

Introduction

This report was commissioned by The West London Mental Health NHS Trust and was a collaborative initiative between the Independent Sector, Health and Social Services.The Letting Through Light project was well supported by the Steering Group, the Ealing User Involvement Project (UIP), as well as the Independent Sector, Social Services and West London Mental Health NHS Trust. The UIP volunteered through the Steering Group to fund the most crucial part of the Project, and to promote the principles of the Letting Through Light Project at every level of the NHS Trust & Social Services.

Ealing User Involvement Project were instrumental in the prompt payment of all Service user / survivor interviewers and Local Co-facilitators and funded the production of this report.

Who did the work?

The Interview work was undertaken by Anil Chopra, Christine Cudjoe, Jaishri Lakhani, Marian O'Brien, Kevin Sasso of the LitTLE Project (Letting Through Light Ealing);

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The Overall day to day running of the project was managed by Role Players Training Consultancy - A London-based Service User/ Survivor only company.

Upon confirmation of the bid's success, we began the work by confirming that localities could contact interested service users/survivors for possible interviewing on the arranged dates.

The bid was submitted on the 4th November 2002 - and confirmed - verbally - in Early March 2003, days before our scheduled starting date of interviews despite efforts to speed up the process!

How were the interviews conducted?

Two interviewers were present at most times for each interview to act as a source of peer support as well as for monitoring of the interview process by the external survivor consultants. On days when there was only one external survivor consultant, it then became necessary to float between two concurrent interviews at the same site - hence our request for two rooms which proved difficult in some venues.

A key learning point for those involved was a need to dedicate specific time during training to working with interpreters. Given the specialist nature of this work, an experienced trainer in the field would have been beneficial.

Use of video was the preferred approach and a high level of training was given to the co-facilitators from the LitTLE Project over a period between September 2002 and February 2003. This was decided after careful consideration of the potential pressure of note-taking while conducting the interviewing process. We also knew that this was a tried and tested method successfully applied in previous research such as “Listen To Us” Stories from Black survivors of the Mental Health System. We thus chose to make video recording our first approach.

We had a provision in the event of interviewee discomfort in the use of this method, to offer only the voice interview to be recorded. Another alternative offered was that notes could be taken by the more experienced external facilitators.

It may be worth noting that we had no complete refusal of the recording process and two participants preferred to be out of shot with only their voice recorded.

Debriefs were conducted at the end of each interview and provided an additional source of support as well as a means of summarising the two facilitators' viewpoints for the writer of the report to capture while the memory was still fresh in the interviewers' minds.

Training for Service User consultants

We ran training workshops for service users consultants involved in the audit work, based on our experience from the Birmingham 'Letting Through Light' Project. In the training, we covered the essential tools required to be part of the Audit Team which subsequently led to the foundation of Letting Through Light - Ealing Project; in short- the LiTLE Project.

The starting point to our training was to unlock the hidden talents as well as rekindle old skills that may have been lost through inactivity in the majority of cases. In view of this, our workshops and focus groups needed to be fun, engaging, enabling and continuously assessing the facilitators' comfort and ability to do the job before our co-facilitators went onto the field. It was essential that people attend at least one of the repeated blocks designed to cover most of the challenges they may face during the interviewing process.

The essential blocks that every trainee had to cover included:

- **getting to know each other;**
- **the 'pros & cons' of service user involvement;**
- **an outline of the Project;**
- **the part the person would like to play in the project;**
- **what support the person required;**
- **what's in it for the person;**
- **facilitation skills;**
- **issues of confidentiality;**
- **health & safety issues;**
- **examples of good practice in User/ Survivor involvement;**
- **"what if" case scenarios;**
- **payments and financial issues.**

The Training Workshops would like to acknowledge and thank all members of the Steering Group for the 'Letting Through Light' Project for their help and support.

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Recommendations from service users

“A 24-hour help-line would be good at the centre.” (IW)

“Deal with the root of the problem and don't just smother the symptoms.” (AW)

“I would like the centre to be open to everyone in the local community not just people with mental health problems.” (AM)

“We need an area in the centre for making music with 'decks'.” (AM)

“Find a befriender, someone who is genuinely interested in you.” (AFM)

“They need a Mother and Baby Unit locally so that kids and mums are not separated.” (AW)

“There should be some Indian movies or satellite TV on the ward.” (MR)

Please note for quotations throughout the report:

IW = Irish Woman
AW = Asian Woman
ACW = African-Caribbean Woman
AFW = African Woman
WR = Woman Refugee
CW = Chinese Woman
BBW = Black British Woman

IM = Irish Man
AM = Asian Man
ACM = African-Caribbean Man
AFM = African Man
MR = Male Refugee
CM = Chinese Man
BBM = Black British Man

Key Challenges for Ealing services from the Audit

Here are some key challenges that came out of the Audit work for mental health services in Ealing for the future.

1. More emphasis on a person's strengths and talents when people first enter mental health services not just a narrow focus on the immediate crisis or problematic behaviours.

2. People who express concerns and worries about their relationships should have assistance to build a supportive network of relationships within their particular cultural context. This should be a focus for any package of assistance. People should also be enabled to talk about forming relationships after their entry into mental health services.

3. More input on knowledge and skills for practitioners regarding suicide and self-harm prevention involving Black and ethnic minority communities.

4. As GP's and the police are often involved with Black and ethnic minority people in crisis, they may benefit from further training around crisis intervention work with this group.

5. What the service user wants should be clearly recorded in any Individual Plan and should form the basis for any package of assistance. There should be safeguards to ensure that people do actually see, understand and agree to their Care Programme plan before it is considered to be a valid document.

6. Routes through to getting help should be made more accessible and easy to understand for Black and ethnic minority communities. Entry to services should not be through one or two professionals but should be more open to self-referral and more widely publicised, especially to non-English speaking service users.

7. Greater access to psychological treatment and counselling for Black and ethnic minority people (in their first language where appropriate).

8. More help and advice required around medication and side-effects for Black and ethnic minority service users. More collaborative approaches to working with Black service users around managing their own treat ment programme.

9. Reviewing safety procedures and dealing with tensions between people on wards, especially around issues of racial and sexual harassment. Explanation of harassment policies to all people coming onto the ward in a way and at a time that is most comfortable for them.

10. Independent advocacy available to everyone entering the ward on an involuntary basis.

11. More consideration and sensitivity in providing care and treatment for women who may have experienced sexual abuse or domestic violence in the past.

12. Privacy and safety provided for children visiting the ward if they wish to keep in touch with parents.

13. The capacity of people to complain or to get redress for being abused or attacked must be strengthened with independent investigation and adjudication where necessary.

14. Greater clarity for practitioners around issues of confidentiality in relation to Black and ethnic minority people and protecting their reputation within their own communities.

15 Expanding the range of activities on wards for people who want this, especially activities that reinforce cultural heritage.

16 Increased usage of family-oriented approaches in mental health with Black and ethnic minority people.

17 Training and information for practitioners around men tal health issues for refugees and asylum seekers.

18 Provide better information about benefits to Black and ethnic minority people (in first language where necessary), especially on discharge from hospital.

19 Better information and skills training around work related issues and return to work for Black and ethnic minority service users.

20 An assessment and planning process that helps people to look at a desirable personal future as well as coping with problems/issues in the present.

1.1 Basic information about the sample of people

A standard set of questions was asked of each person and it was emphasised that people could refuse to answer any question that they felt uncomfortable about. Here are some basic facts about the sample of people we talked to.

The sample was fairly evenly balanced in terms of gender.

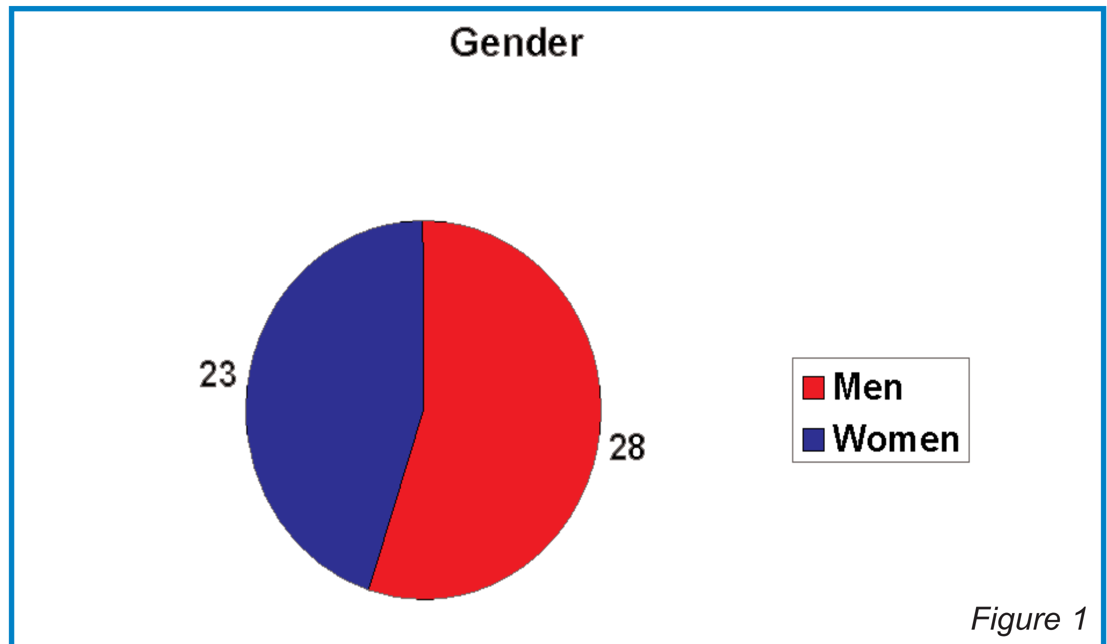
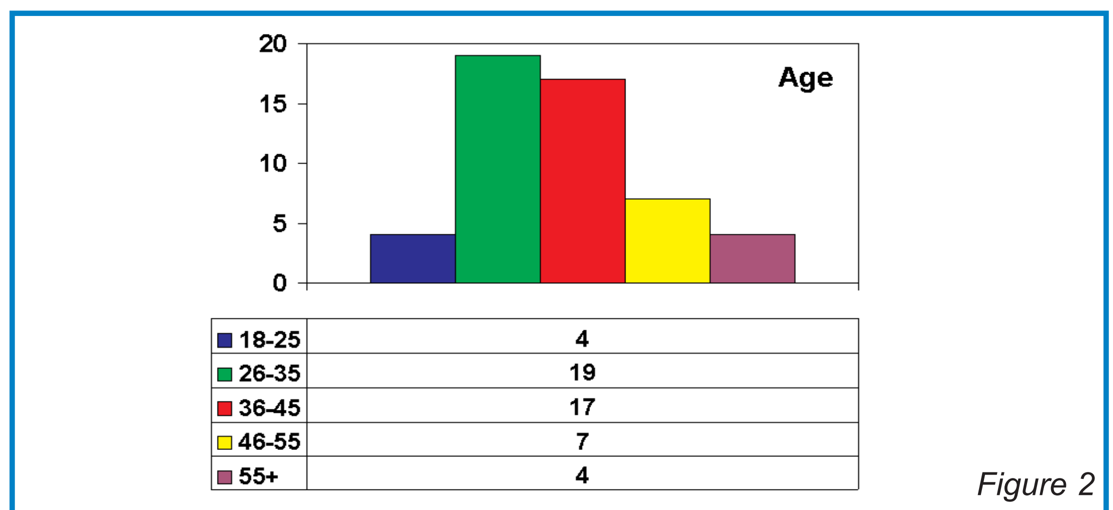


Figure 1

Approximately 70% of the sample were between the ages of 26-45.



Age	
18-25	4
26-35	19
36-45	17
46-55	7
55+	4

Figure 2

1.2 Ethnicity

People were asked to state their own ethnicity. Although the African-Caribbean group is the largest single 'ethnic group' (representing 23%), the Asian and British-Asian group would be the biggest (representing 29%). Further analysis would be required to determine whether this sample represents the actual ethnic breakdown of mental health service users in Ealing and how that compares to the general local population.

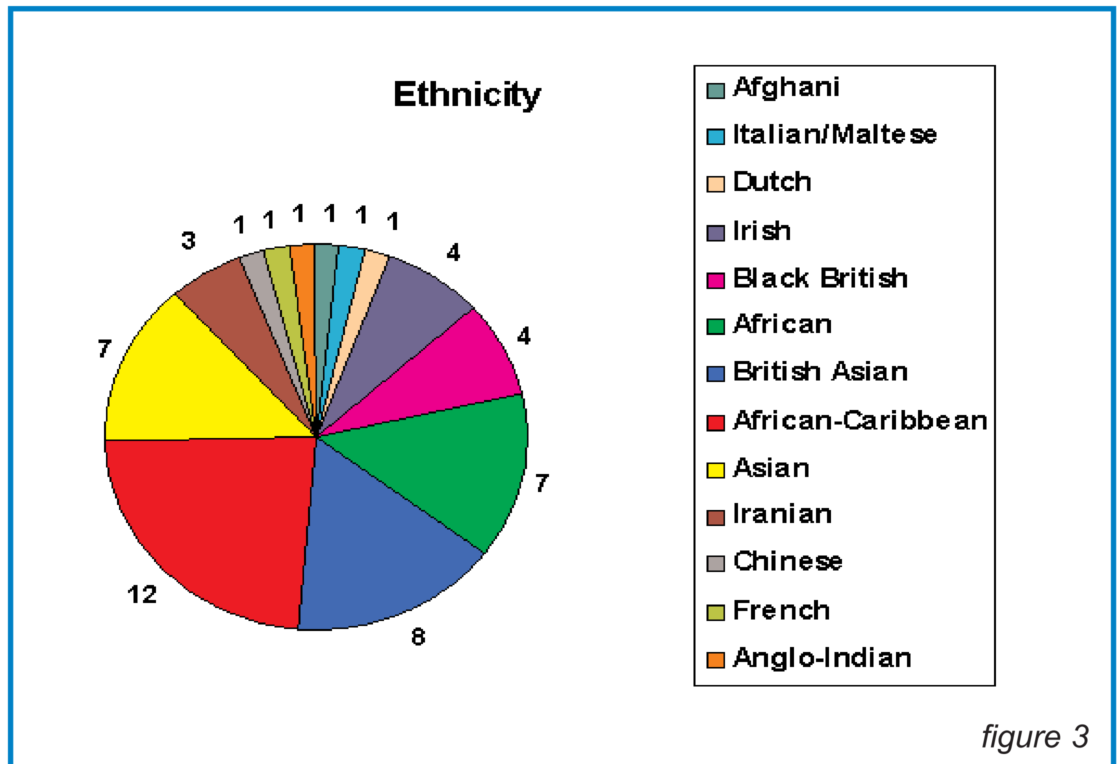


figure 3

1.3 Language

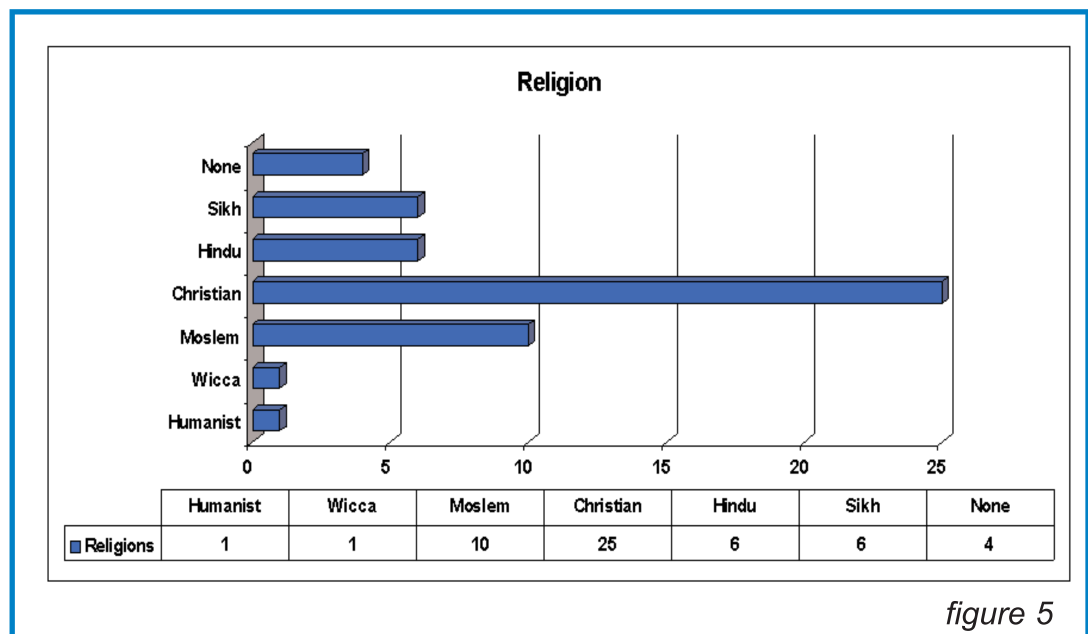
The vast majority of people interviewed could speak English and required little help with reading or writing. However, there were some people who required interpreters and these people seemed to have had some of the worst experiences of mental health services in Ealing (and elsewhere in London).

English	43	Hindi	1
Patois	2	French	1
Ugandan	2	Gujerati	2
Somali	2	Urdu	3
Cantonese	1	Punjabi	8
Farsi	4		

figure 4

1.4 Religion

Nearly half of the sample was Christian and a few said that they believed in more than one religion.



	Humanist	Wicca	Moslem	Christian	Hindu	Sikh	None
Religions	1	1	10	25	6	6	4

figure 5

2.1 Quality of Life & Mental Distress

The pattern of answers to this question was very similar for men and women. It is interesting to note that 9 people felt that the quality of their lives had remained the same or improved since their experience of mental distress with 5 people reporting their lives were significantly better. A lot seemed to have depended on the quality of their childhood and family experience.

Quality of Life Before & After Mental Distress

	Men	Women
Lot worse	17	13
Little worse	6	6
The same	1	1
Little better	1	1
Lot better	3	2

figure 6

2.2 Confidence building

"I used to be a teacher. It felt good when one of the nurses talked to me about high school and asked for my advice." (AW)

The need for personal development and a sense of achievement in people's lives was evident from most people interviewed. Despite having gone through some difficult and painful experiences most people expressed the desire to progress and improve their lives. A precursor for personal achievement is a sense of confidence and positive self-esteem.

Practitioners can get caught up in just responding to crises and becoming reactive in the way they practice. A more proactive approach to practice is not only more effective it also enables service users to take a more positive and optimistic look at the options in their lives.

"It meant a lot to me to perform a song for the other people at the day-centre." (BBM)

"I have a sense of neglect by family and services - they need to show you that you are more than a statistic." (AFM)

"I used to work in hospitals. It was a big blow to be on the other side - very depressing." (AW)

2.3 Relationships

"After hospital, my friends brought me back slowly into their circle - we are equals now." (AFM)

"I now worry about when I meet someone for the first time do I keep the 'mask' on or do I take it off?" (AM)

A most important factor in helping people to remain in the community after experiencing a period of mental distress is for them to have a growing network of supportive relationships. Services need to do more on helping people to form and maintain their personal relationships. There were a striking number of young people in the audit who expressed fears about making and keeping relationships after they have been given a mental health label.

"I often hide the fact that I have a mental health problem." (ACM)

"I haven't had a girlfriend for years." (AM)

"I'm worried about relationships with girls when I have a mental health problem." (AFM)

"Since my mental distress I've had to make a whole new set of friends - I've found it difficult." (BBM)

3.1 Early Contact with Mental Health Services

More than half the sample had entered mental health services through their GP with one quarter entering through police involvement. Most people had entered as a result of a severe crisis.

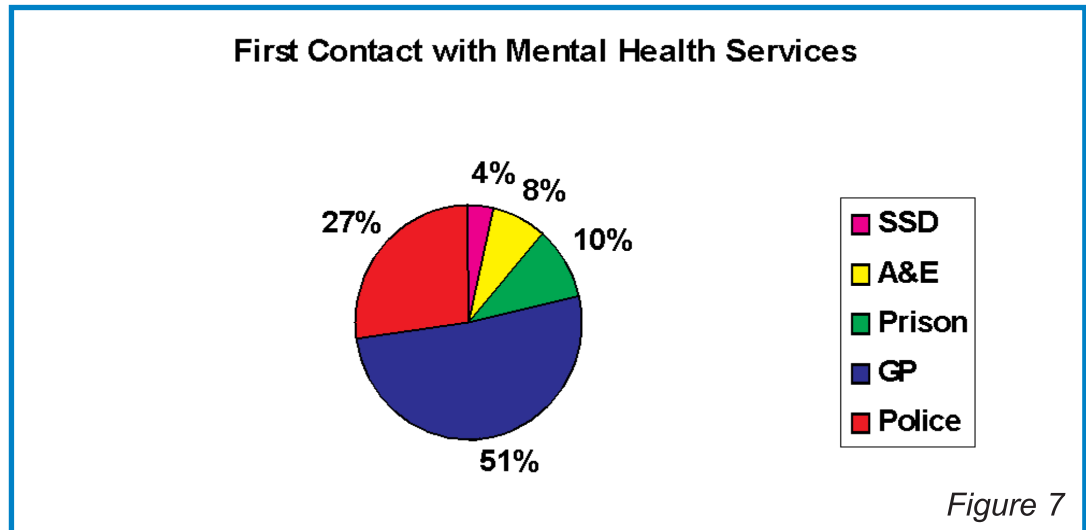


Figure 7

Altogether 54% of people found their first contact to be satisfactory to very good.

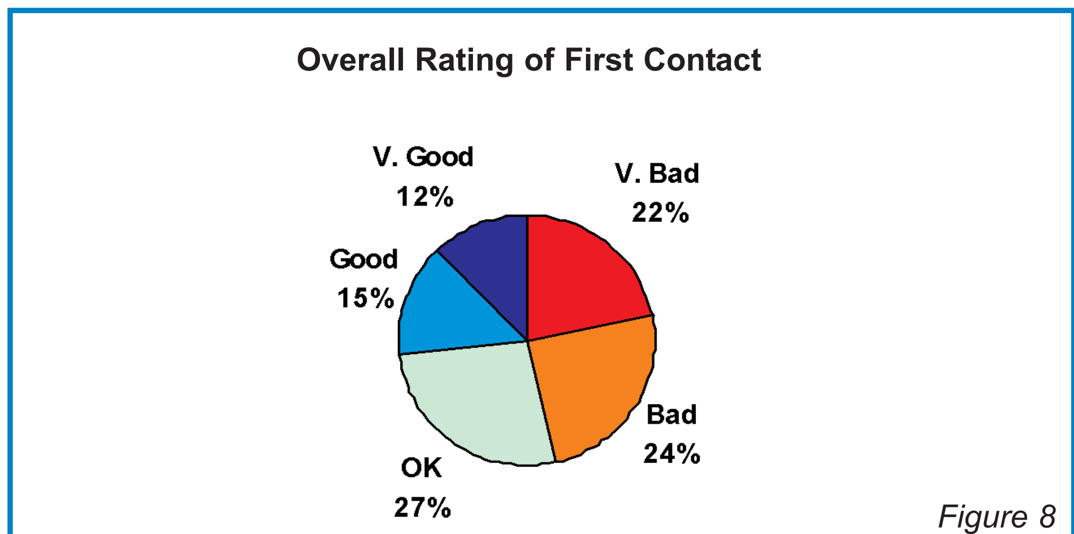
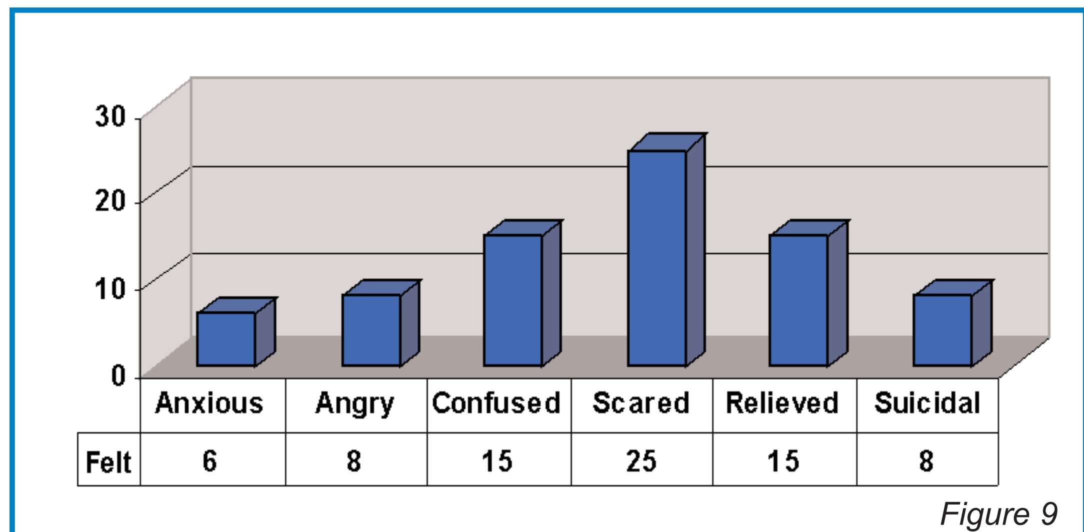


Figure 8

Over half of the sample found their first contact to be satisfactory to very good which is surprising considering that most had experienced a severe crisis during this time.

3.2 Feelings on First Contact



	Anxious	Angry	Confused	Scared	Relieved	Suicidal
Felt	6	8	15	25	15	8

Figure 9

Half the sample of people also reported being scared rather than any other emotion with a significant number reporting suicidal feelings at the time of their entry to services (8 representing 16% of the sample).

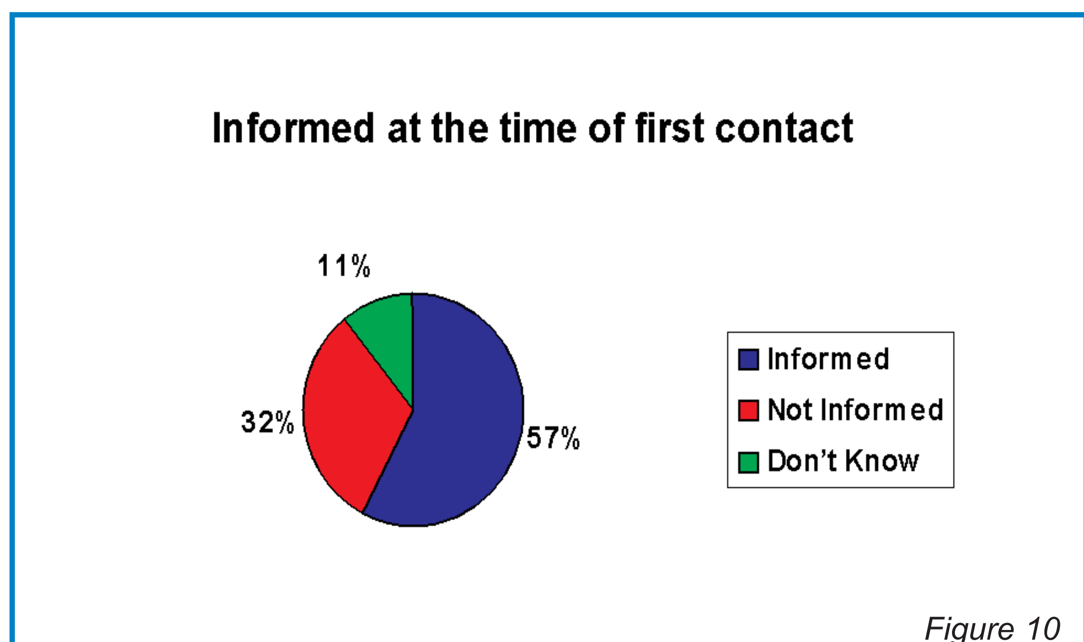


Figure 10

3.3 Describing distress

We felt that it would be interesting to ask people how they would describe their mental distress as a clue to what they see as their priorities.

"I've got a wife but I feel wife-less, I've got a house but I feel homeless and I've got money but I feel poor." (AM)

"When a woman cries there are tears in her eyes. When a man cries his tears stay in his heart they don't come out." (AM)

"I'm unstable like water." (AM)

"The days are too bright and the nights are too dark. (AW)

"I cry all the time, I can't sleep, I don't like going outside and I fight with my family for any small reason." (AW)

"I get the 'horrors' and can't trust anyone." (AM)

"My thinking goes wrong and gets muddled." (AM)

The house feels empty - we don't sit together as family anymore. (AM)

3.4 First Contact with Ealing Services

Over three-quarters of the sample found Ealing services to be satisfactory to good with nearly 40% finding them good or very good. These are much higher percentages compared to figures for first contact with 'any mental health services' asked earlier.

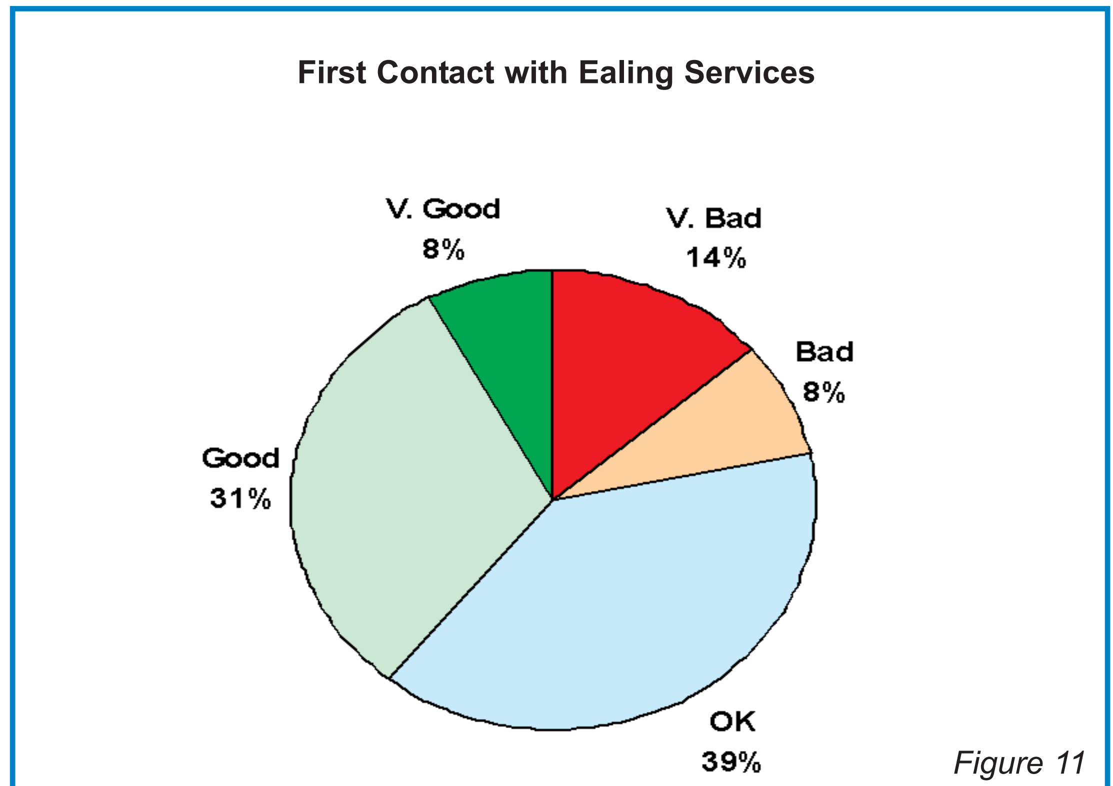


Figure 11

4.1 Getting help

"I wanted to be allowed to grieve for the loss of my relationship, my job, my place in society. Grieve naturally and have someone listen to me not 'zonked' with drugs." (ACW)

"One member of staff went out of he way to take me down to Abbey National to get some money out and help me to send some clothes and toys to my daughter." (ACM)

"Because of the professionalism of the mental health people I felt that I was helped to understand my problems. People were genuinely interested in my welfare for the first time in my life." (BBM)

Mental distress is experienced by individuals in many different ways, so it is important to have many different responses by practitioners in providing assistance to people.

The first step for any practitioner must be to listen to what the service user wants and take it very seriously. The question asked should not be 'can we do this?' but 'what is stopping us from doing this?' and 'how can we remove these barriers?' Help offered has to be seen more from the service user's perspective if there is going to be a genuinely more participative and empowering approach to service provision.

Most of the service users interviewed did not have unrealistic expectations but modest dreams that are achievable. Neither is there a demand for a huge amount of extra resources in many of the comments made, it merely requires practitioners to give the service user's views much higher priority in the way help is offered. It may also mean that practitioners will have to rethink their priorities in their everyday work. It was the excellent bits of practice by a few individual practitioners that made a huge difference to the quality of experience of the service users concerned.

"I'm a vegetarian and I lost a lot of weight because I wasn't eating properly. The cleaner on the ward, who was an Indian lady, made sure that I had a little to eat." (AW)

"I don't think that I have mental health problems. I just need support in the right places." (ACM)

The staff really tried to do things professionally on the last occasion I was there (in hospital). (ACW)

"I went to the doctor (GP) and he thought that I was OK and he sent me home - I was seriously suicidal at the time." (CW)

"They're only concerned that I take my medication." (ACM)

"There was an older African nurse who walked with me. He talked to me like father to son. I respected him. I felt it in my heart." (AFM)

"I love X (worker at centre) so much. He has changed my life. He allows me to look after the plants and flowers. I love that." (WR)

The most brilliant help I got from the SSD and the Trust was them finding a nursery for my one year old. In those days I got myself an education and eventually a job and all the while I was on medication. It gave me a chance to have a life. (AW)

"I would rather have been at home supported by a counsellor." (AW)

"I felt very saddened that I had to ask for help." (BBM)

"I thank God that He has shown me the way to get to this centre. I feel like I belong." (WR)

"I stuck two leaves on a New Years card for the doctor and he invited me to come to the Art Group that's how I got in - I really like it." (WR)

I was offered psychotherapy but I couldn't go because I couldn't get child-care. (AW)

"If you make a noise they pay you attention but if you keep quiet they treat you like a pawn." (ACM)

"I didn't like my CPN - he was like a 'robot'." (AW)

"The vicar and church helped and supported me." (AW)

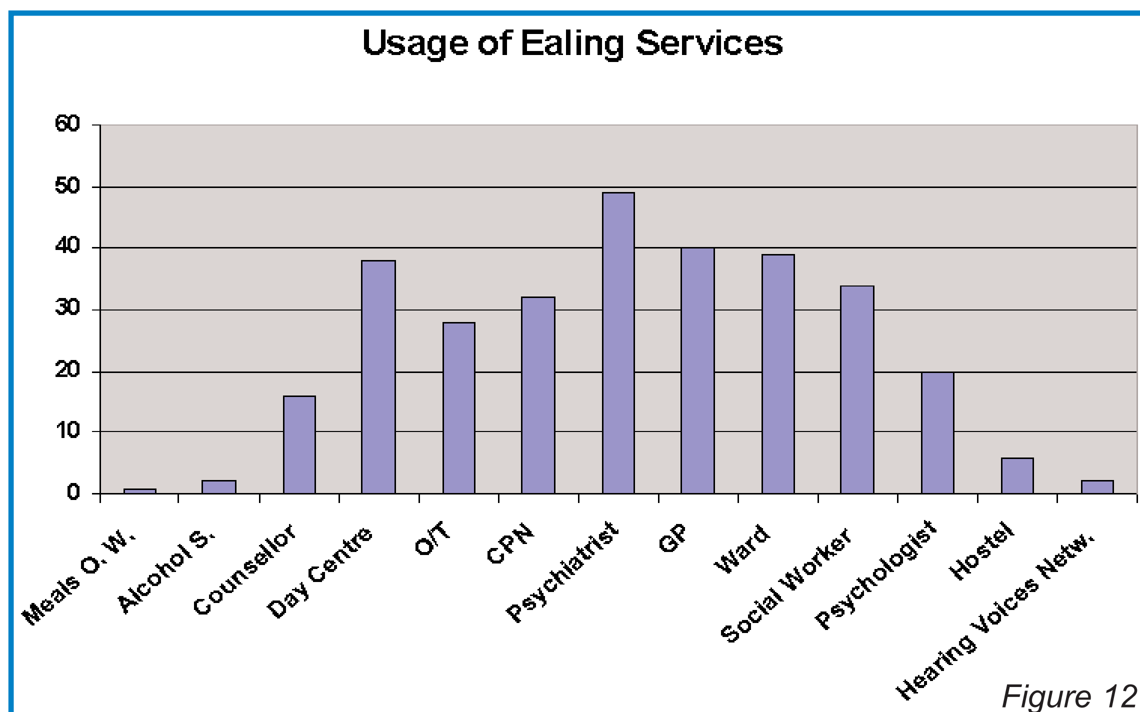


Figure 12

4.2 CPA

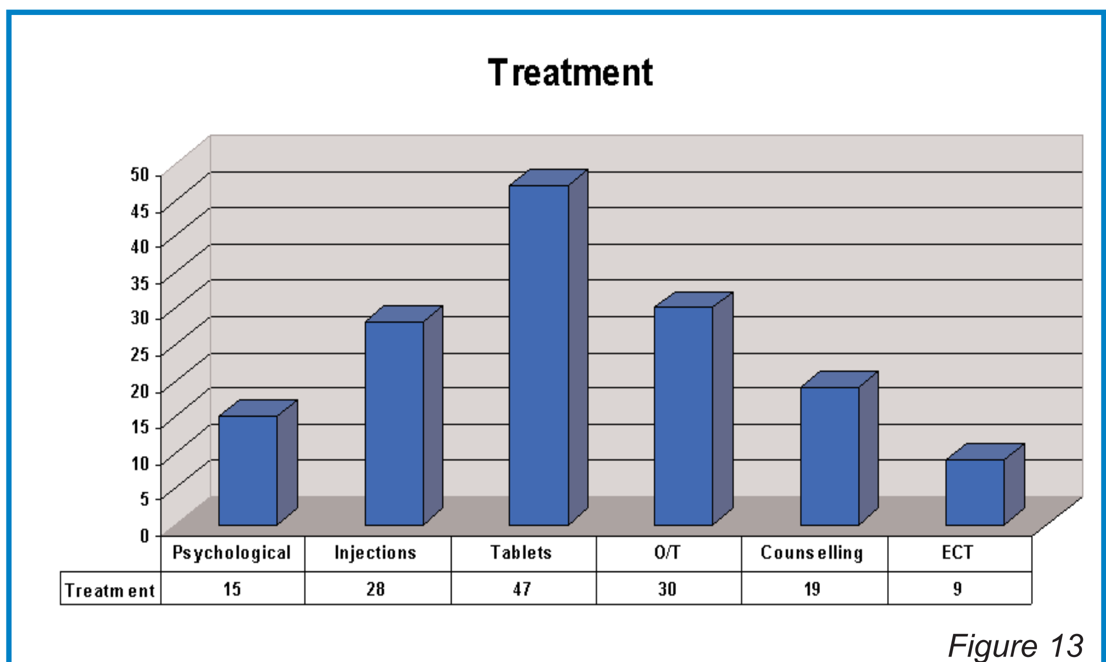
We asked people what they understood by the Care Programme Approach. A lot of people had not even heard of this phrase and others had very little idea what it meant. We have set out some of the best answers to this question here.

"CPA - Doctor comes around to see my progress and see if I'm going to harm myself or others." (CW)

"CPA - Staff recognising a person's needs and asking the person how they can improve life and get them back into the community." (BBM)

5.1 Treatments for Mental Distress

By far the most often used treatment was medication in the form of tablets. Counselling was made available to only 37% and psychological intervention to only 29%. These two forms of treatment had by far the best satisfaction ratings by interviewees, especially psychological treatments.



	Psychological	Injections	Tablets	O/T	Counselling	ECT
Treatment	15	28	47	30	19	9

Figure 13

5.2 Side Effects

A large number of people (58%) reported that their side-effects were severe and described them as 'bad' or 'very bad'.

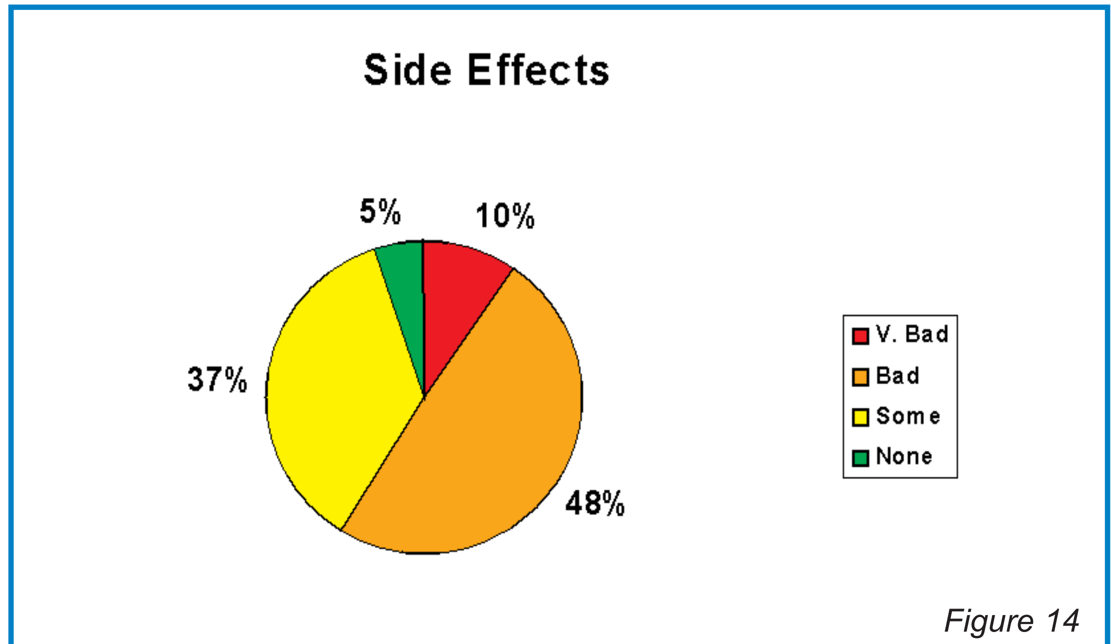


Figure 14

By far the greatest concern about side-effects was weight gain with well over half of the sample, followed by involuntary movements or shaking and sleep disturbances.

Descriptions of side-effects

Weight Gain	Shaking	Eyesight Prob.	Locked Jaw	Panic	Low Sex Drive	Pains in Joints
27	12	3	3	5	3	2
Skin Prob.	Hunger	Hair Loss	Slowing Down	Sleepy	Feeling dulled	Disturbed Sleep
4	6	2	7	10	3	3

Figure 15

Side effects of medication appeared to be a concern to the vast majority of people. For some people it had led to risky behaviours such as stopping medication suddenly or experimenting with other non-prescribed drug or alcohol solutions. People felt that there had generally been a lack of accurate information about medication and its side-effects. Many people seemed to put more faith in the opinion of people who had been using the drugs rather than professionals.

This tendency could be capitalised on by training mental health service users and survivors as people who can screen people who are having problems with their medication and helping people to access expert advice.

"They pinned me down to watch TV. They said 'SIT!' like a dog - but the drugs had affected my eyes and I couldn't see properly." (AW)

The most severe and worrying side-effects were associated with the administration of injections and to some extent ECT. Often without the consent of the people subjected to the treatment. Several people who were injected claimed that they were 'allergic' to the drug in question to some degree. A significant number of people believed that when they reported their side-effects they were not taken seriously.

There is no doubt for some people that side-effects had a big impact on their quality of life and family relationships. Many were not keen to come off medication altogether but to adjust type and dosage to their particular needs.

More attempts to work collaboratively with people in deciding and managing their medication has to be a priority for the practitioners involved.

"I had been on the ward for some time and I had the wrong dosage of drugs, my hands were jumping about. My husband asked a passing doctor and he said that my drugs were probably too strong. So they reduced them eventually. They should have monitored them properly. (AW)

I feel my dosage is too high but if I don't take it they will 'section' me. (CW)

I stopped taking my medicine and I suddenly became very ill - it was serious and no-one knew. (WR)

6. Contact with Police

People were asked if they had experienced contact with the police in relation to their mental distress. Nearly half of the sample had made contact and of those people 73% reported a satisfactory or good experience. This is a high satisfaction rating in relation to the police compared to many areas and other known research studies. It would be very interesting to do further investigation about what it was that made contact with the police good. Any good practice lessons could then be disseminated to other police forces.

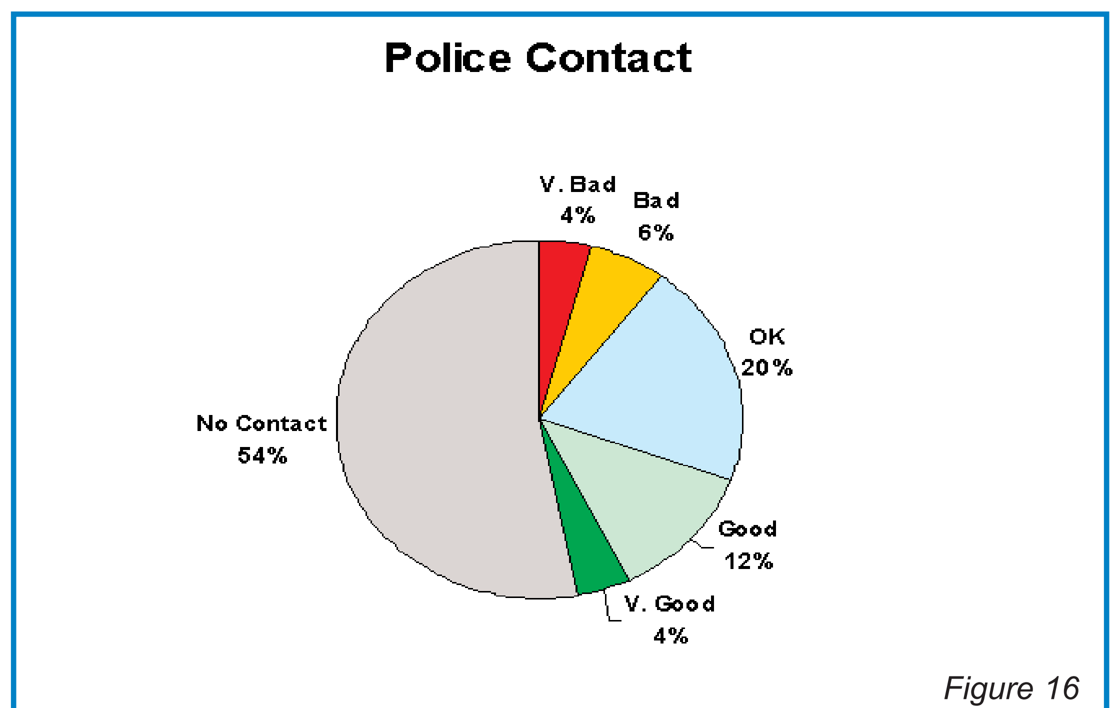


Figure 16

Police Contact (numbers)

V. Bad	2
Bad	3
OK	10
Good	6
V. Good	2
No Contact	26
Total	49

Figure 17

7.1 Stay in Hospital

Many people were unclear about the length of their stay in hospital. Of those who did give a time 18 (or 41%) stayed for under six months. Several people had been in hospital for over one year including some who had stayed for over three years or more. Some of these people included those who were transferred from prison to hospital.

Length of Stay in Hospital

Less than 2 weeks	2
2 weeks-1 month	5
Up to 3 months	6
3-6 months	5
6 months-1 year	1
Over 1 year	8
Unknown	17

Figure 18

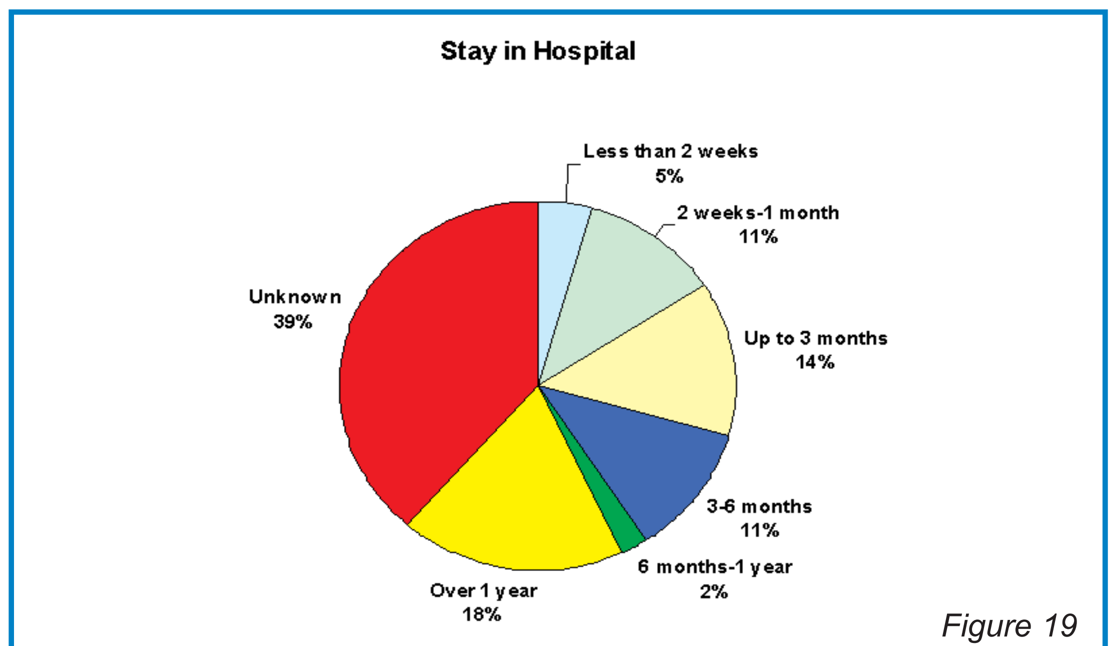


Figure 19

7.2 Experience of the Ward

The physical environment of the ward was found to be acceptable or good by the vast majority of people. However, 73% of people thought that the ward was stressful and 41% felt unsupported on the ward.

Views of Ward Environment

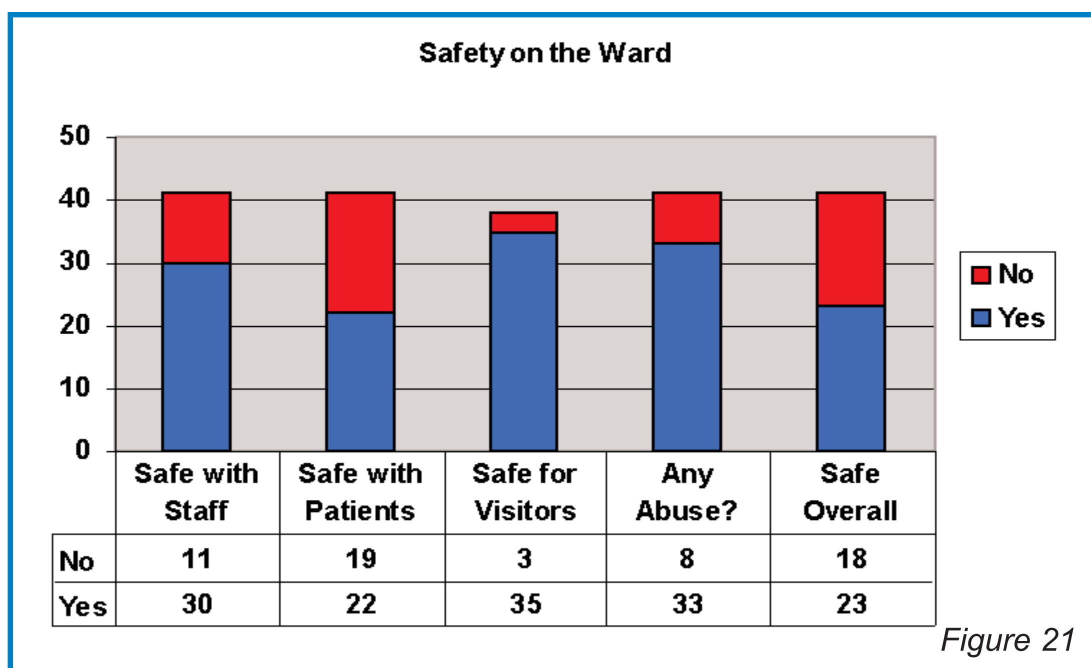
	Yes	No
Comfortable	35	6
Clean	34	7
Noisy	15	26
Spacious	33	8
Stressful	30	11
Supportive	24	17

Figure 20

7.3 Safety on the ward

"Male patients became over-familiar and took advantage of the vulnerability of women on the ward." (ACW)

Over 73% of people felt safe with staff on the ward but this figure drops to about 54% in relation to patients. It must be recognised that about 43% of people did not feel safe on the ward.



	Safe with Staff	Safe with Patients	Safe for Visitors	Any Abuse?	Safe Overall
No	11	19	3	8	18
Yes	30	22	35	33	23

Figure 21

“A degree of physicality was part of the culture of the ward and I found it very intimidating.” (AM)

Many safety concerns centred on other patients but there were some serious incidents involving practitioners that have been left out due to considerations around confidentiality. The incidents included physical as well as sexual abuse of people when they were at their most vulnerable. Most have been reported but the person subjected to the abuse has not been informed of any outcome of investigations in all cases reported to us.

Safety for women is further complicated by their previous experience of sexual abuse or domestic violence. Consideration of a woman's background and past experience must be taken into account by practitioners if there is a need to restrain or forcibly treat her.

Threats and violence by patients on other patients must be more carefully dealt with and monitored. Several people rated the ward or day centre a dangerous place solely due to the behaviour of one or two other service users.

“One woman on the ward had a habit of throwing hot drinks over people.” (AW)

“You can't complain to the police because they won't believe you if you're on a psychiatric ward!” (ACW)

“Since the influx of refugees and non-English speaking people in the hospital I've noticed more violence, racism and thuggery from staff on the ward.” (AM)

“The receptionist speaks to you through a grille when you first arrive at the centre - as if everyone's dangerous. It's an automatic slur before you walk through the door.” (IW)

“All the people restraining me on the ward were men - I was really scared.” (ACW)

“I was punched in the face by a White nurse.” (ACM)

“I was scared on the Prison psychiatric wing. I couldn't speak English and someone tried to rape me there.” (AFM)

7.4 Relationships with Hospital Staff

Most people found the staff to be friendly, polite (58%) and felt that they did talk to them on the ward (71%). However, people were less convinced that staff had got to know them to any real degree (54%). It was worrying that we had 19 people (46%) who had felt intimidated or were sometimes intimidated by staff.

Views of Staff Approach

	Yes	No	Sometimes
Polite & Friendly	24	7	10
Talk to you	29	12	0
Get to Know You	19	22	0
Intimidating	5	22	14
Informed You	23	18	0

Figure 22

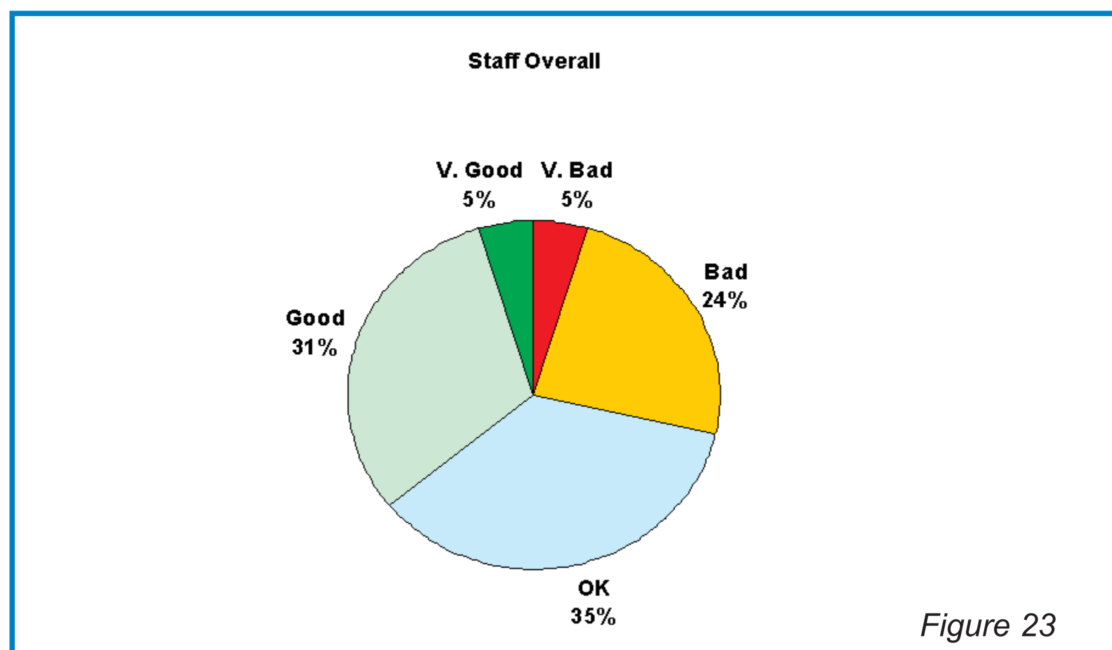
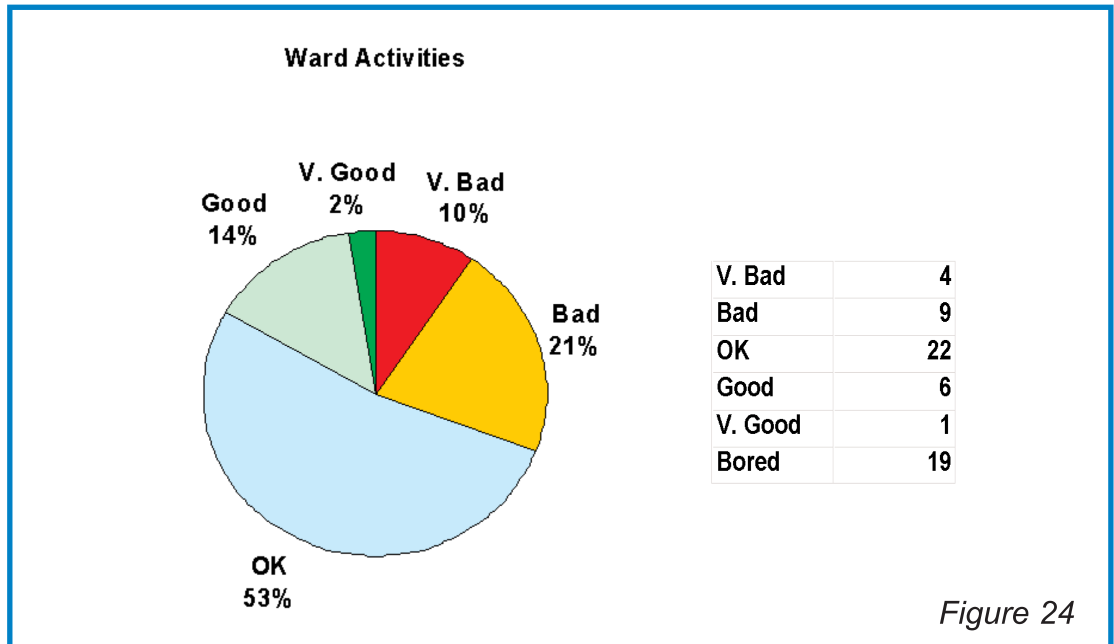


Figure 23

7.5 Activities on the Ward

67% of people felt that ward activities were satisfactory or good but this figure consists of 53% who saw ward activities to be of average quality and could certainly be improved. 46% of people stated that they had been bored on the ward for much of the time.

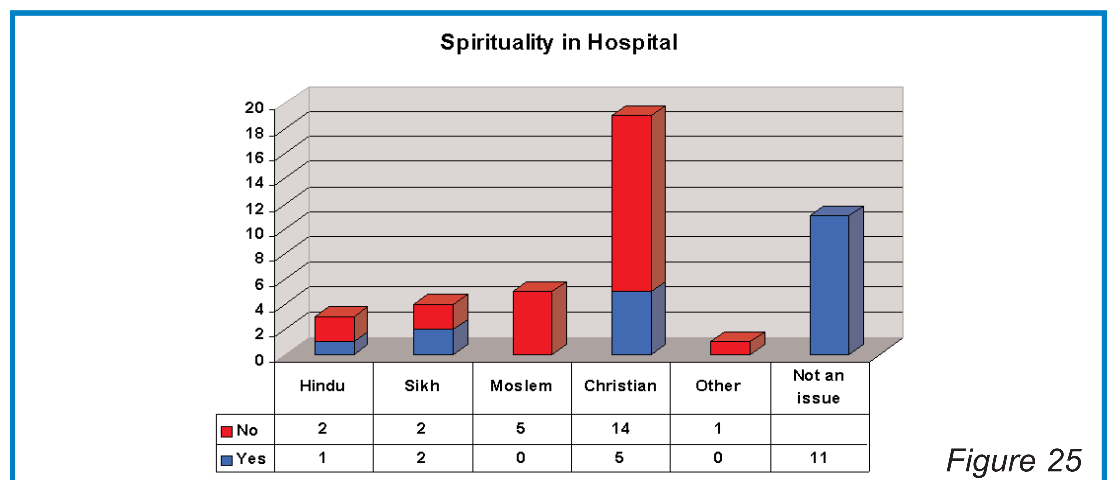


V. Bad	4
Bad	9
OK	22
Good	6
V. Good	1
Bored	19

Figure 24

7.6 Spirituality in Hospital

Three quarters of people who expressed a view that spirituality was important to them felt that it had not been taken seriously in hospital service settings. Three quarters of Christians and all Moslems did not feel that their spiritual beliefs were taken into account in their care.



	Hindu	Sikh	Moslem	Christian	Other	Not an issue
No	2	2	5	14	1	
Yes	1	2	0	5	0	11

Figure 25

7.7 Freedom to go out

People were asked if they could go out to get some air whenever they wished while on the ward.

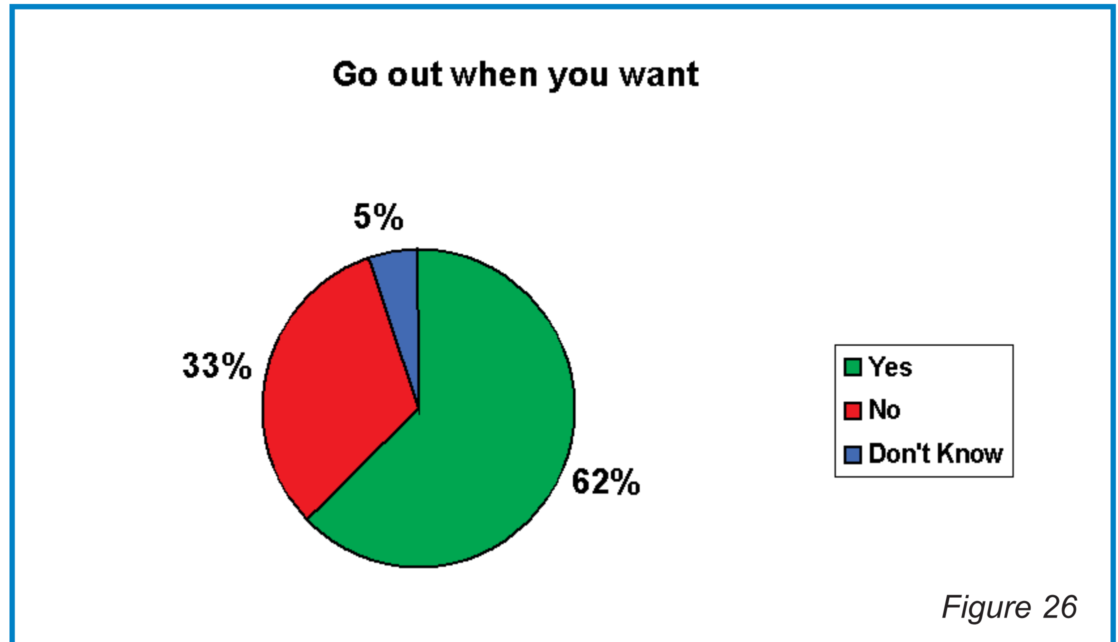
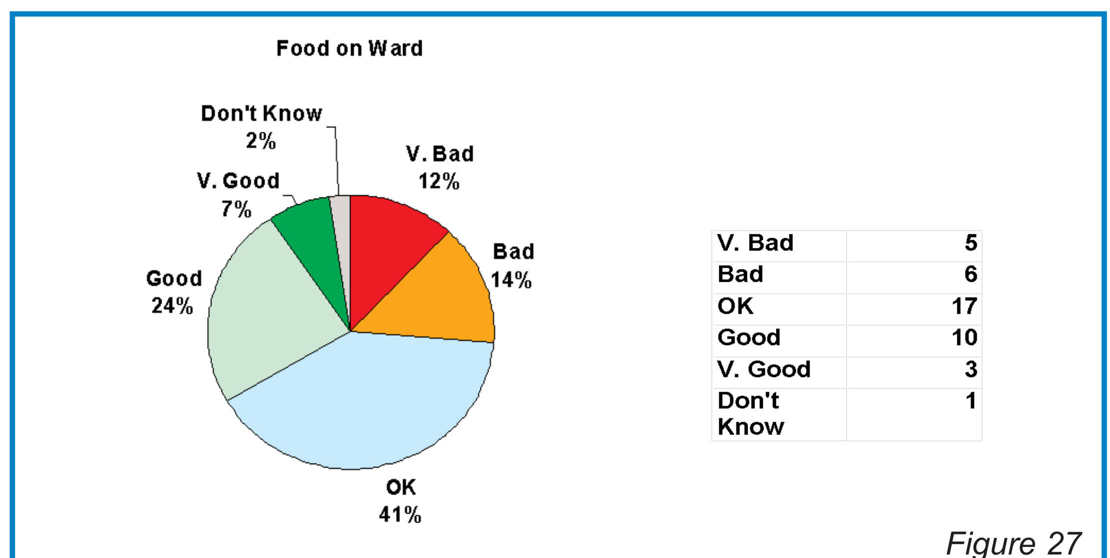


Figure 26

7.8 Food on the ward

72% of the sample found the food in hospital to be acceptable to very good. This represents quite a high satisfaction rate.



V. Bad	5
Bad	6
OK	17
Good	10
V. Good	3
Don't Know	1

Figure 27

7.9 Hospital

An overwhelming majority of people interviewed felt that hospital was satisfactory, good or very good for them. Many said that they were less positive at the time as it was a distressing event for them but they recognised that hospital was the only real option for them at the time of their crisis.

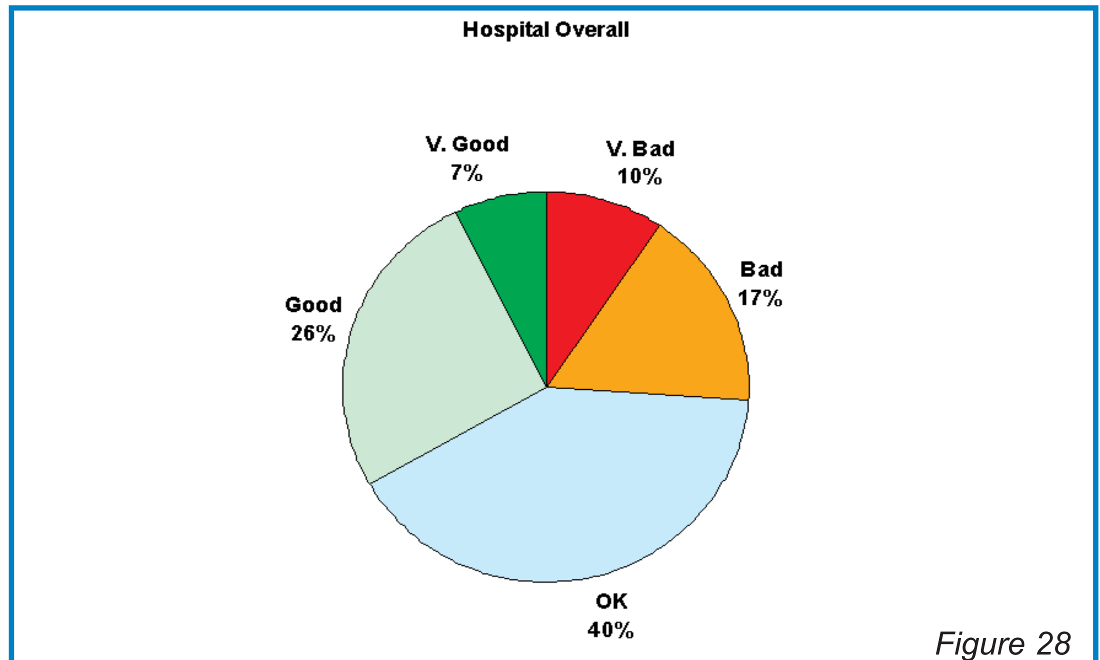


Figure 28

8. Confidentiality

When I got caught by the police, the doctor told me that I'm not allowed to stay in this country. He phoned the Home Office and saying that I had committed a crime and that I was 'mentally ill'. (AFM)

There were some examples of worrying breaches of confidentiality by practitioners. Service users were confused about how confidential information about them really was in the mental health system.

“The doctor disclosed to my employer that my ex-husband was a 'druggie'. That had nothing to do with the job I was applying for.” (IW)

“I wasn't told about my diagnosis but my father was.” (AW)

9.1 Family

Most of the people had some serious worries or concerns about their families (78%). However, over 72% said that their family had not received any support from any services. Over 70% of people said that they had received support from their families before and after experiencing mental distress.

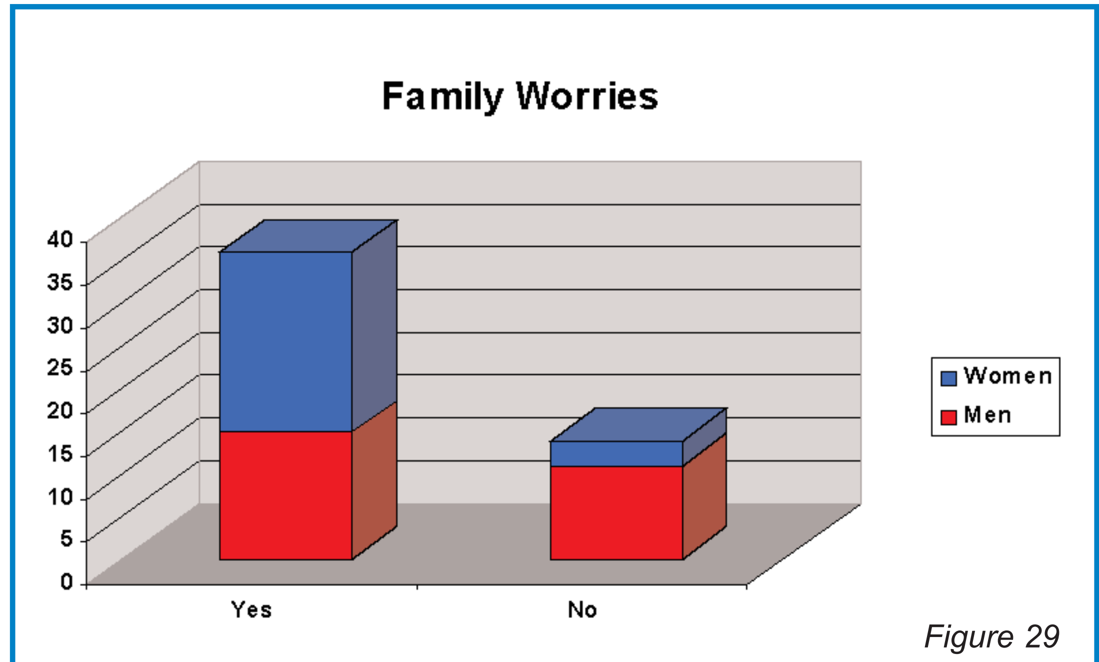


Figure 29

Worried about family

	Yes	No	Totals
Men	20	7	27
Women	20	3	23
Don't Know	1		1

Support from Family

	Yes	No
Before Distress	37	9
After Distress	36	10
No Contact	5	

Support for Family

Yes	No	Not Needed
6	37	8

Figure 30

Families feature prominently in people's recovery from mental distress, even those people who have lost contact with their families expressed a wish to make contact again. It appears that this major resource for recovery is generally ignored by mental health services.

“They never ask me questions about my family.” (ACM)

Practice involving family-based approaches should be studied more and expanded in working with Black and ethnic minority people as several cultures give families a higher priority than in modern British cultures. General mental health services can operate in a more family-oriented approach by closer liaison with practitioners who specialise in this area. There will, of course, be different challenges thrown up by this approach, as families can be the source of much conflict and stress for service users as well as a force for recovery.

“My problems affected my son - his exams results suffered. It was a big shock to all my family, like a death in the family”. (AW)

“The doctor didn't want to talk to me directly, he wanted to talk to my parents.” (AW)

“My husband says 'you are sick and you are going to make me sick'.” (AW)

9.2 Parenthood

“My baby was taken away from me. Social workers have attacked me at every step - no wonder people don't report mental distress.” (IW)

Many interviewees said that they were concerned about their children, especially the women with children. A few women explained how being a mental health service user was a liability when it comes to getting assistance from social services with child-care. Many parents were worried about having their children 'taken into care' if they asked for any help.

Parents with older children were concerned about how their mental distress had impacted upon their children. There was a sense that many parents saw themselves as a burden on the family which added to their distress. The role of parent was important for all of those who had children and was a source of pride

“I want a tiny flat near my daughter so that I can have contact with her and my grandchildren and some privacy.” (WR)

“I want my kids to be proud of me. I've just published a book of poetry.” (ACW)

10. Solidarity

"When I was homeless I found others from my country. We walked like a 'tribe' and we looked after each other." (AFM)

Many people felt that they would be more comfortable with a member of staff from their own background. The main reasons stated centred around feeling easier to communicate with staff and having a better chance of staff understanding the person's cultural background. Some people did say that it was more important that staff were 'better at doing their job' rather than ethnicity or colour being important. There were a few people who would actively prefer someone from another ethnic background and this was largely due to fears about confidentiality and personal and family standing in the community being jeopardised.

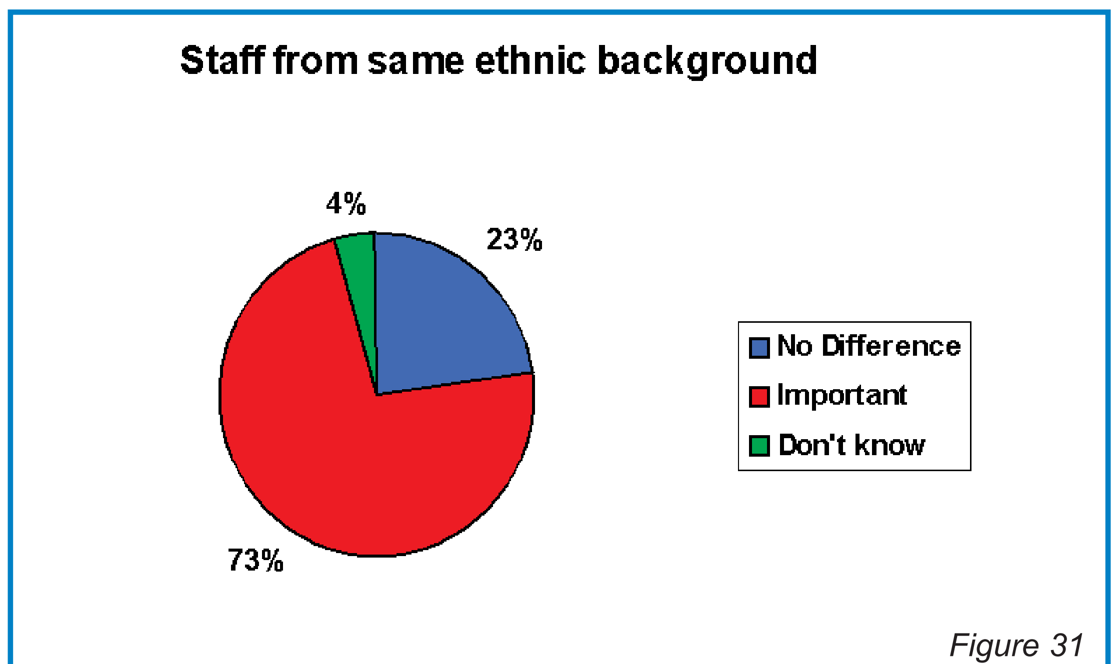


Figure 31

"I was singing a song in the smoking room and when I turned around everyone was singing along with me. It was so uplifting." (AFM)

"It made me feel much better talking to someone who has been through it." (AW)

"This is the first time I've talked about it." (AW)

"Having a Black woman psychotherapist was very helpful." (ACW)

"There was a Black nurse from Grenada and I felt that I could trust her even though they said I was paranoid." (ACM)

11. Culture

It is not straight forward to provide a culturally appropriate service to a very diverse community of people but there have to be some key principles for practitioners to follow and some minimum standards set for good quality service to groups that are culturally different from the majority in communities.

Some of the problems arise through a misunderstanding and lack of knowledge about the concept of culture itself. There may be simplistic approaches to culture by practitioners that result in stereotyping or confusion for Black and ethnic minority service uses.

"In my culture we usually greet people by kissing them on the cheek. The doctor wouldn't take me off section until I stopped doing this as he said that I was being 'over-friendly'." (ACW)

"They didn't really take my culture into account - One patient told me to think of Rama and line up for my medication." (AW)

"I've learned to put up barriers to survive it." (IW)

12. System vs. People

Several people felt that on occasions they were not treated with respect by practitioners. This could often arise from a rigid and bureaucratic approach to applying procedures or a lack of forethought about the impact of a change in the system.

The implementation of management decisions and operation of systems may not be avoidable but practitioners can use their skills in carrying out these procedures with humanity and empathy. Many people appreciated the pressures that practitioners were under but wanted to be treated with respect.

"The Asylum Team have put me into a small room, miles from my daughter and grandchildren. I have no privacy, no TV and I'm very distressed." (WR)

"I was allowed to go home for a few hours and when I returned to the ward they had put all my stuff in a bin bag and left it outside my room. They told that they needed the room, they had even thrown out my chilli sauce brought by my husband - it was mine." (AW)

"I have an important letter from the Home office and its in English so I can't read it. I've asked my daughter but her English is not very good either." (WR)

Someone told me when I was homeless that if I pretend to be mentally ill I will get accommodation. I pretended and they gave me a strong drug and locked my jaw. (AFM)

After being there 18 months on the ward I still had no room of my own and I was always being moved around from one ward to the next, sometimes nightly. (MR)

13. Power games

Over one third of people thought that their treatment in hospital was more about control rather than care.

“I don't tell my social worker that I cut myself because she has threatened to take my children off me if I do it again.” (AW)

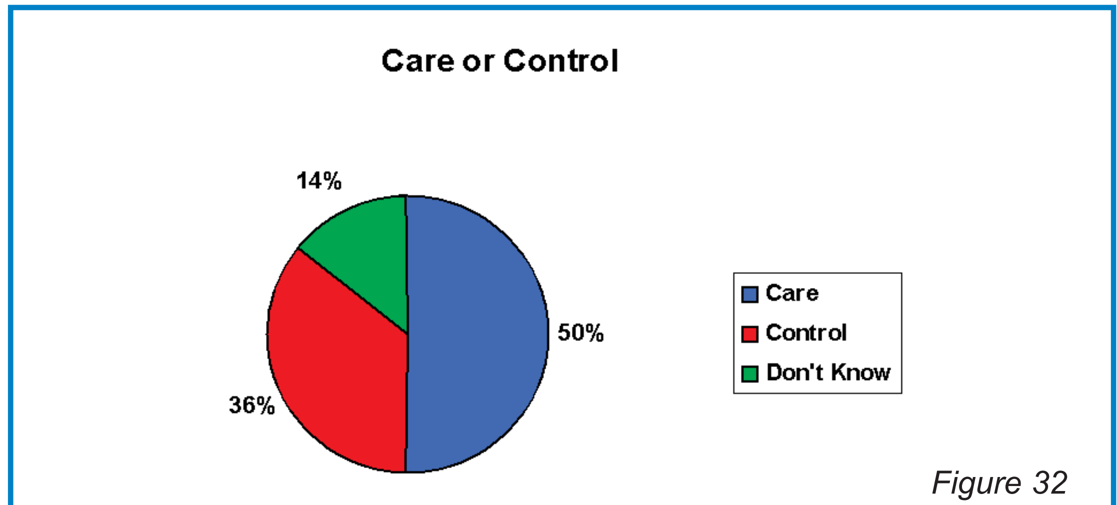


Figure 32

Power dynamics between practitioners and service users is central to the issue of trust and without trust mental health services cannot function. Practitioners who play the power game will not function very well with Black and ethnic minority service users as they will quickly detect this and play the game themselves.

“I smelled drink on the nurses breath. I got into an argument with him when I made a joke about it. He pushed me hard in the back, then pushed the panic button and they came and held me down and injected me.” (AFM)

“I can't trust anyone anymore, I've been betrayed so often - so many broken promises.” (WR)

“I wanted to get out so I never went against the doctor.” (AW)

“The psychiatrist said to me ‘What are we going to do with you? Your family is your problem.’” (AFM)

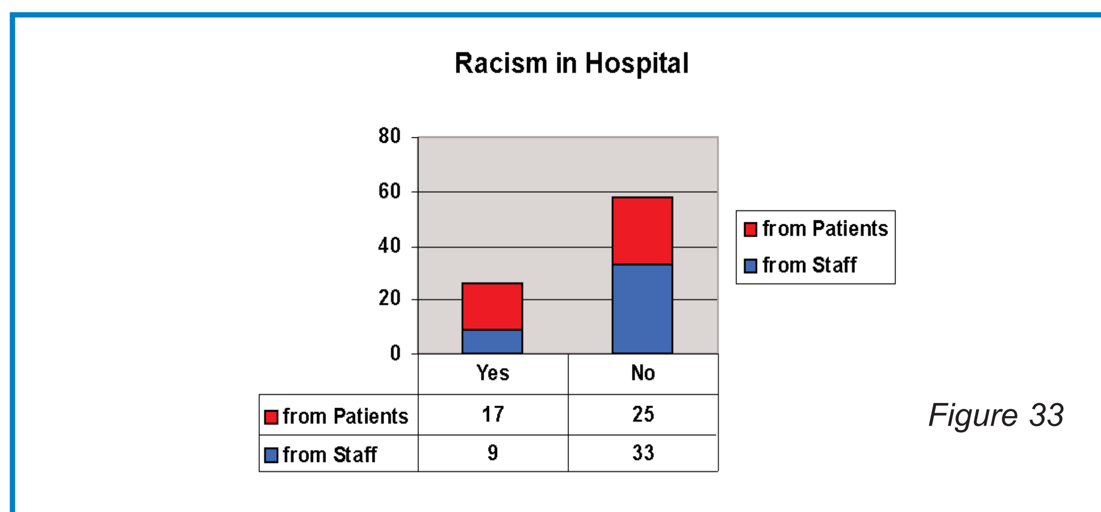
“I told my doctor about a drug that has helped me in the past but she wouldn't listen to me and put me on another one which didn't help me.” (AW)

“If a White patient complains about a Black staff they get the sack but not the other way around.” (AFM)

“The woman at the office made me feel bad about getting my Benefit. I cannot explain how terrible I feel when I go to get my £30 benefit for the week.” (WR)

14. Personal Experience of Racism

40% of people had experienced racism from patients on the ward and 21% from staff in hospital-based services. The corresponding figures for day and residential centres were 6% from other service users and 3% from staff (see Figure 34).



	Yes	No
from Patients	17	25
from Staff	9	33

Figure 33

15. Stereotyping

There were various stereotypes coming up from people's stories such as non-English speaking people being regarded as unintelligent or Black men being unable to talk about their feelings or women being able to cope with child-care despite any distress they may be going through. Practitioners who fall into the trap of believing these stereotypes and worse still, acting upon them, engage in discriminatory practice and lose credibility and trust with service users at the point when they most need to provide them with help. This process is what is behind the recent findings of the Sainsbury Centre's 'Circles of Fear' report.

"They judge you by your clothing. If you look good they think that nothing is wrong with you." (ACM)

They push me towards Black issues all the time at the centre. (ACM)

"They look at Black people with mental health problems as the worst of the worst." (ACM)

16.1 Day Centre & Residential Experience

There were extremely high levels of satisfaction with most of the day centres and residential facilities used by Black and ethnic minority service users (94% rating satisfactory to very good with over 81% rating them good or very good). However, there were strong criticisms of a few centres and residential places in Ealing but people tended to 'vote with their feet' and find another centre that did suit them.

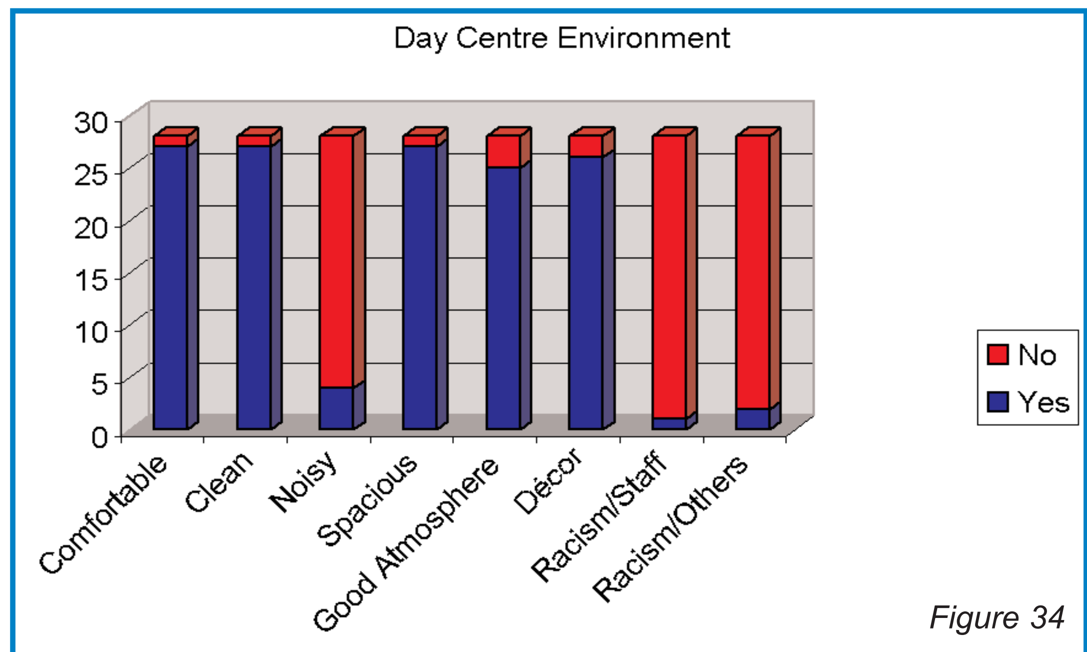


Figure 34

Altogether 54% of people found their first contact to be satisfactory to very good.

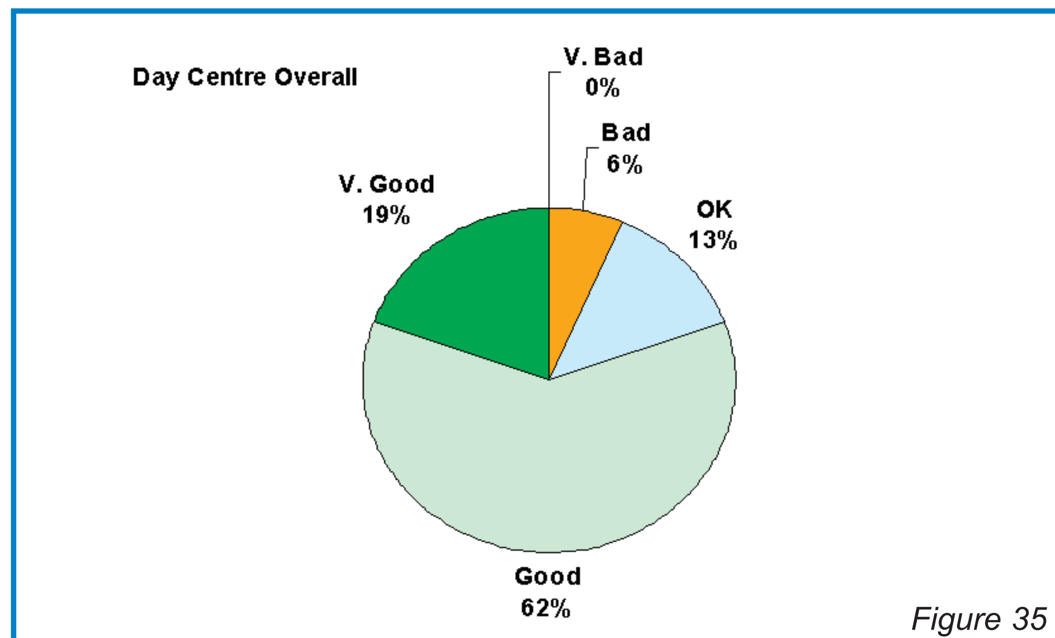


Figure 35

16.2 Name badges

The question of staff wearing name-badges was one that many people had not thought about before but the immediate reactions were quite positive with 46% thinking that it was a good idea. There were a high number of 'don't knows' so it may require a wider survey of views. There are considerations of protection of service users' rights here where they can directly identify staff whom they may wish to complain about at a later date.

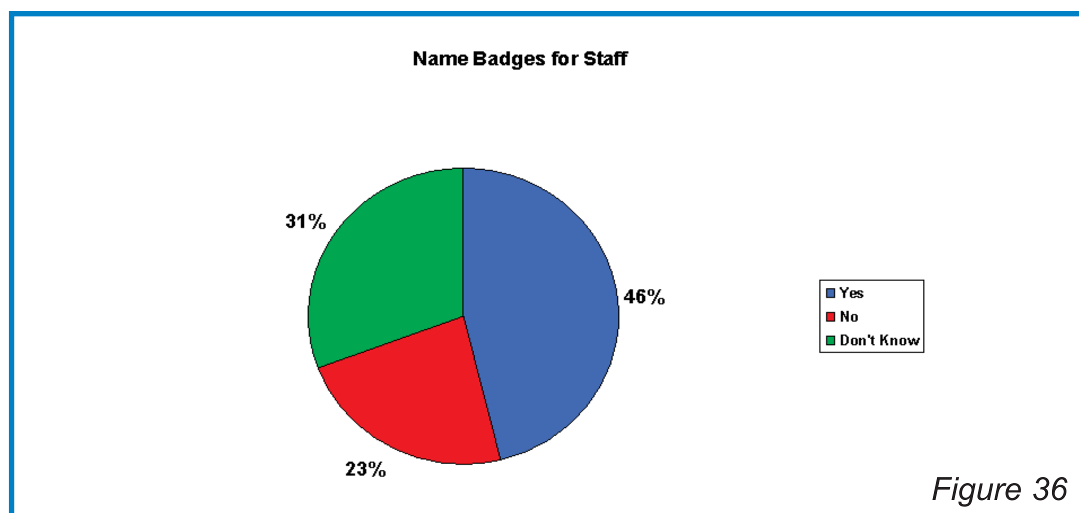
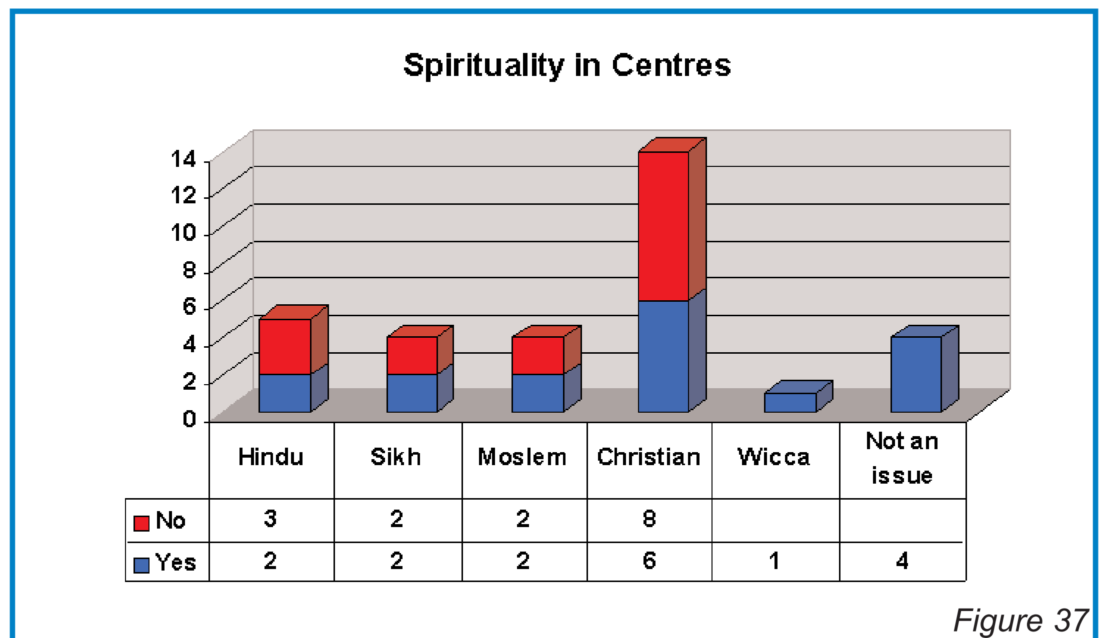


Figure 36

16.3 Spirituality in Centres

57% of Christians and approximately 50% of others felt that their spirituality had not been taken seriously at their centres. This compares to 75% of Christians and all Moslems in hospital settings.



	Hindu	Sikh	Moslem	Christian	Wicca	Not an issue
No	3	2	2	8		
Yes	2	2	2	6	1	4

Figure 37

For some people spirituality was extremely important for others it wasn't an issue. At times of mental distress, spirituality can be an important aspect of a person's recovery.

"I prefer people who give spiritual advice. They are more compassionate than professionals and see you as a human being and not just a patient. People in hospital should get more access to them." (AW)

"When I talk to the nurse about my beliefs, she says 'you're bashing the Bible again'". (AM)

"I wasn't allowed to have things in my room - they swept things off my altar." (ACW)

"My diagnosis is not correct. My mental health problems are a side effect of spiritual transformation - I take no tablets." (AW)

16.4 Activities at Centres

The vast majority of people felt that activities at the Centres were acceptable to very good (80%) with 36% feeling that they were good or very good. These are again high satisfaction rates but several people said that they did want more variety in activities offered (including some more culturally appropriate options) and there were some complaints about existing equipment not working such as pool tables, televisions etc...

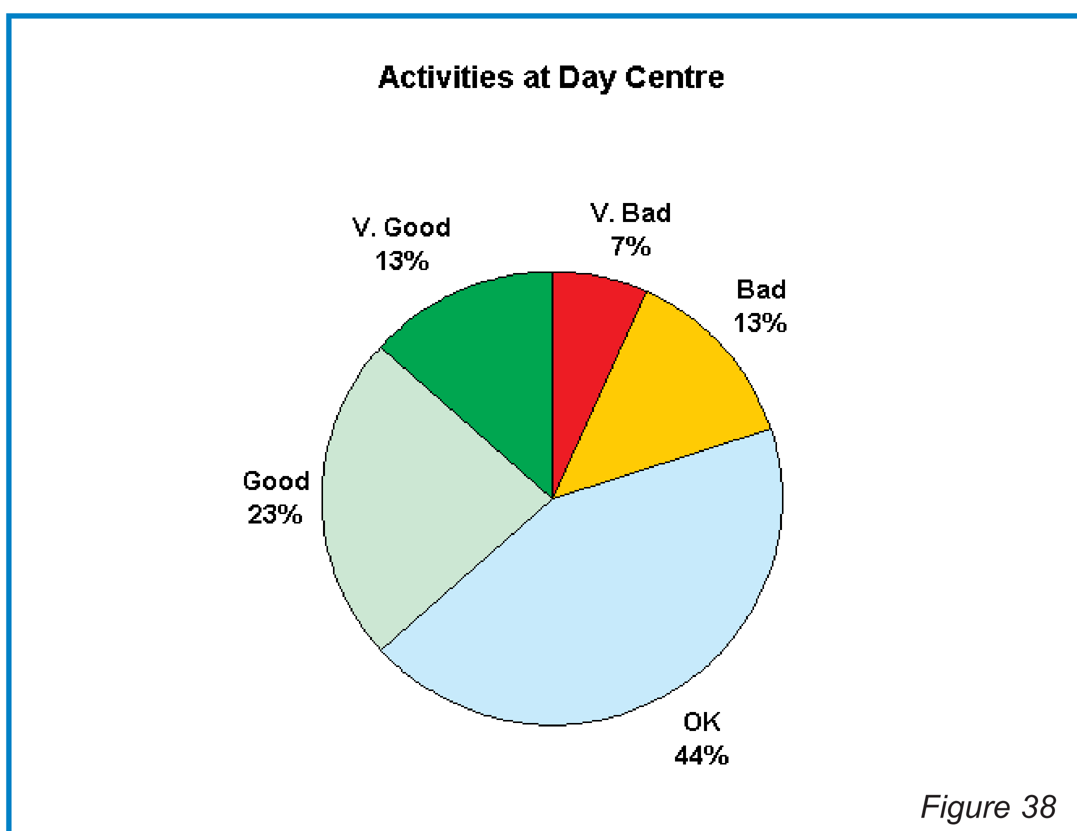


Figure 38

17.1 Information

"I'm taking 14 tablets a day at present and I still don't know if I should. I've asked to see a doctor for the past six months and still haven't managed it. I'm now taking cannabis and alcohol to alter my mood. (MR)

There were just over half the people interviewed who rated the information acceptable in relation to diagnosis, medication and benefits. Although, generally people felt that there was little or inaccurate information about diagnosis and medication which they considered to be most important. The greatest levels of dissatisfaction were with information about work (55% not acceptable) and family issues (63% not acceptable).

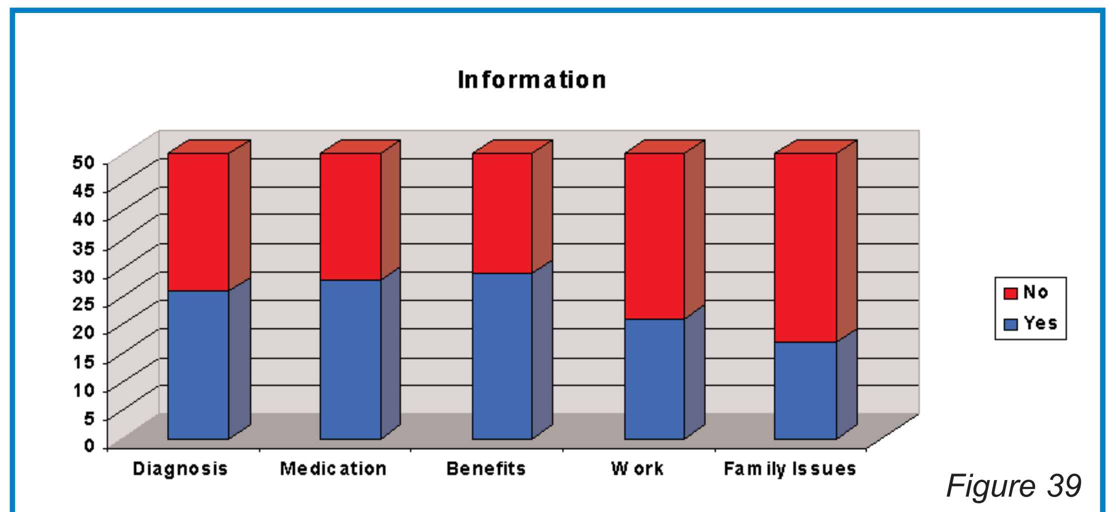


Figure 39

The level of information given to people was found to be very variable with some people reporting that they had received excellent information and advice and others saying that it was abysmal. We have not really discovered what was behind these very differential experiences of people. However, there appeared to be some information services that people found to be extremely helpful.

"I want more information - I've been in this country for 2 years and I've just found out about Meals-on-Wheels." (AW)

"I didn't know I had a Care Plan until recently." (AW)

17.2 Information about benefits overall

People were asked to comment on the overall quality of information about benefits, and there were quite high rates of dissatisfaction with 45% feeling that information was either bad or very bad. Considering the importance of this issue for mental health service users generally, there needs to be further investigation of the barriers to good information about benefits for Black and ethnic minority people.

“I've been given a diagnosis of 'chronic schizophrenia' but when I claimed for DLA the doctor refused me because I was too well!” (IW)

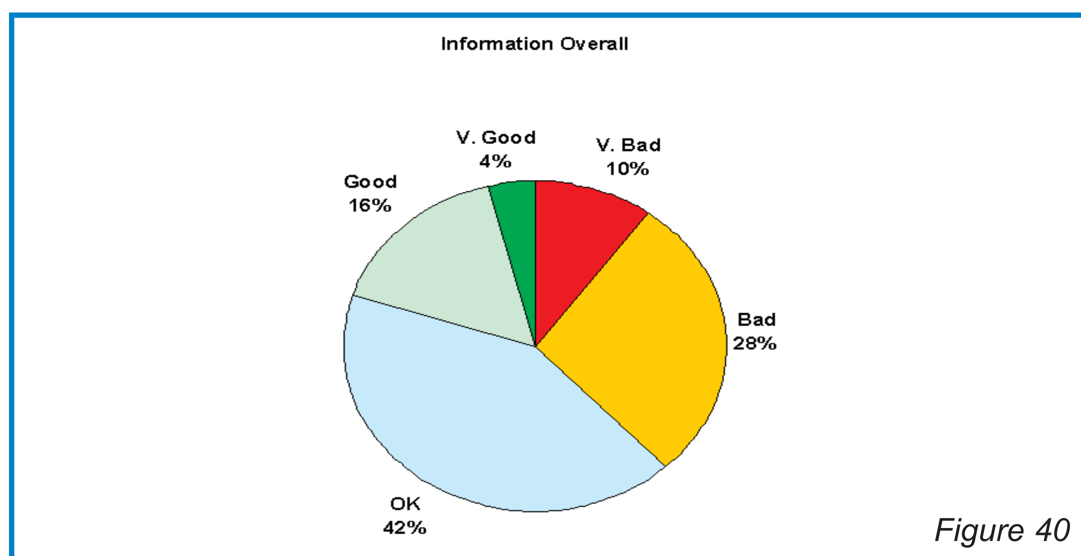


Figure 40

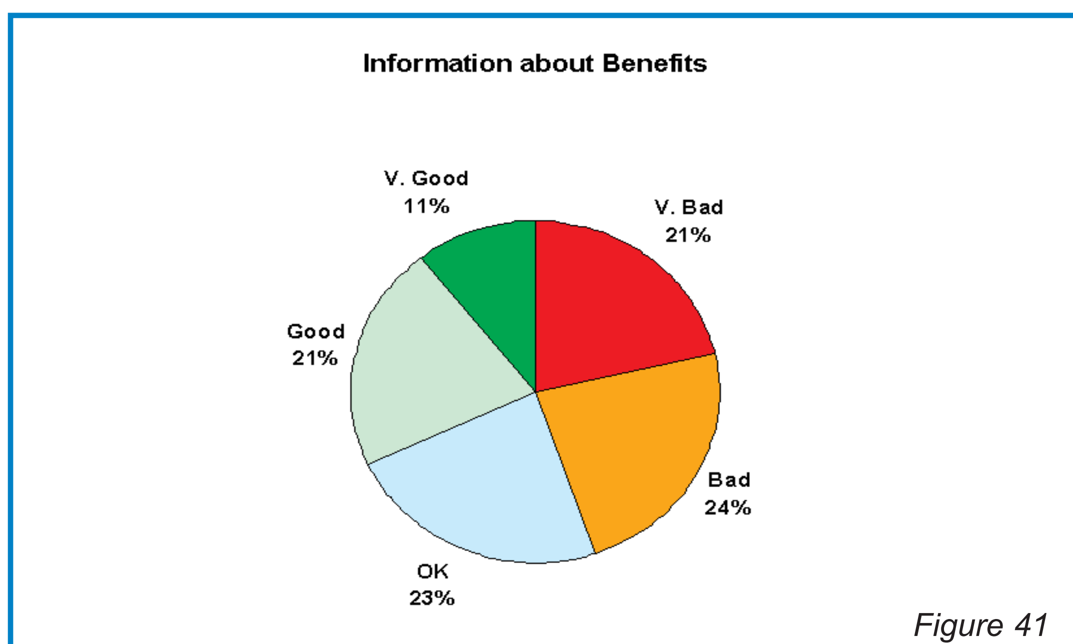


Figure 41

Several people had experienced problems with getting their benefits but many did not get very good information or advice about this. Some people did describe getting excellent advice but this needs further investigation to find out where they got help.

A service user-led initiative on this issue would be interesting looking at whether people do get their correct benefits, the result of appeals and the review of people's changing circumstances. The issue of Direct Payments for mental health service users could also be looked at.

18. Job stress

Stress arising from employment and work roles is a common source of mental distress, especially in the areas of racial and sexual harassment and workplace bullying. Several people were struggling with unresolved past bad experiences of work or current problems of working under a psychiatric label.

People appeared to want more information about returning to work and coping with the demands of work. Mental health service users and survivors are much more likely now to challenge discrimination in applying for jobs. An increasing number of mental health service uses will require training and support from practitioners about their rights, applying for work and surviving the demands of work, paid or voluntary.

"I worked hard with refugees. It was a huge burden listening to their stories - some of them horrific. It rubbed off on me." (AW)

"They have been employing me for ages at this company but now that I have this label, I'm not sure what will happen." (AW)

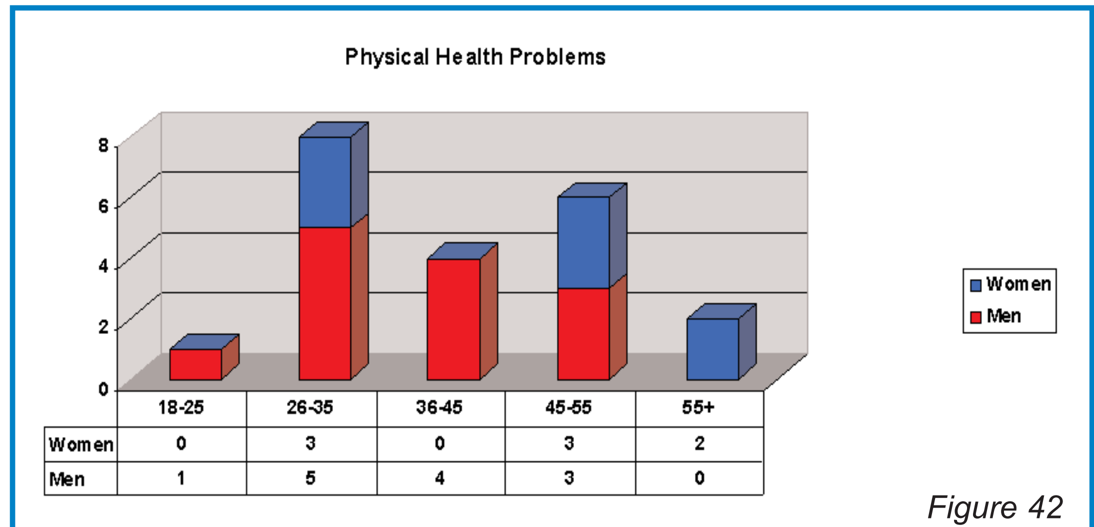
"They said that I couldn't cope with work and they effectively sacked me." (AW)

"I suffered racial harassment at work - my heart used to pound every time I saw the woman who abused me." (AW)

19. Physical health

I was limping and had a swollen foot so they gave me antibiotics which made no difference. It was only because I wanted to join the gym and needed to have an OK from the Doctor so he decided to send me for an X-ray which revealed a broken bone in my foot! (AW)

There were 13 men and 8 women in total who had physical problems that they were very worried about. There were 9 men between the ages of 26-45. Although this represents a small number of people in the overall sample the mental health of the people concerned was very much influenced by their health problems



	18-25	26-35	36-45	45-55	55+
Women	0	3	0	3	2
Men	1	5	4	3	0

Figure 42

There were some people who were most concerned by their state of physical health and, indeed, some people who entered a period of mental distress due to a physical health problem or injury. A few people had not received adequate help with their physical health problems and were very worried by the lack of progress on treatment.

It may be necessary to promote a targeted physical health campaign, including sight and hearing, for mental health service users in the community and on wards.

20. Hopes for the Future

It was encouraging to find that most of the people interviewed were relatively optimistic about the future. Most had plans to develop themselves and improve their lives. Having dreams for the future gives hope in the present and helps people to come through their current difficulties.

Services need to assist people to think about their future and not just totally focus on surviving the present.

"My hope for the future is that I allow myself to make mistakes." (IW)

"I want people to accept me for what I am, give me a chance to work again and be a successful member of the community." (IM)

"I want to be with normal people but then what is 'normal'?" (ACM)

"They tell you that you cannot get work, you cannot study and that you will never get better." (ACM)

"I want more balance in my life." (AFM)

"I want to get into human rights like Oxfam, the UN or Red Cross." (AFM)

"I want to set up a dress-making business." (ACW)

"I want to do something useful. I'm willing to work as a volunteer in the garden at the hospital." (WR)

"I want peace in myself and accept I have a mental health problem." (W)

The unique nature of this audit was that it was designed and led by Black and ethnic minority service users. The level of connection, the quality of communication with the service users being interviewed and the information collected was greatly enhanced as a consequence. What became apparent was the great benefit people derived from talking to someone who not only understood the experience of racism but also had been through an experience of mental distress. The interviewers brought their skill and experience to the situation and demonstrated to people a positive way of using an experience of mental distress to help others.

Many interviewees expressed a real thanks to the interviewers and appreciated the unique opportunity they had been given to talk about their experiences with people who really understood them. The role modelling provided by the interviewers also acted as a powerful inspiration for other service users that they can recover and contribute to the good mental health of others.

The more that Black and ethnic minority service users are supported to take on training, consultancy and research roles such as these the more we will provide useful role models for others.

Looking ahead

This report can be used as an agenda for action with groups of stakeholders, such as Black and ethnic minority service users, practitioners from Health and Social Services, families and carers, voluntary sector groups and Black-led community groups. The 'Key Challenges' can be prioritised and reduced to a few high priority targets for local service development plans. People can then come up with ideas about how to achieve these targets. This process has been successfully tried in Birmingham through the 'Letting Through Light' project there.

Report by Peter Ferns
(August 2003)