PATHWAYS REPORT

Experiences of Mental Health Services from a User-Led Perspective

Pathways

Experiences of Mental Health
Services from a User-Led Perspective
(Based in Galway City)

Sponsored by the
Western Health Board

In conjunction with
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Acknowledgements

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Personal Notes from the Research Team

Louie's Pathways Research Route
The paper mountain blues, the volume of reports/literature, the constant drafts /redrafts of every period of the research and getting agreement with the team members was for me the hardest lesson learnt.

Going down cul-de-sacs, and some dark alley ways and realizing that professional help are not mentors and almost all the work had to be done by the team was upsetting yet uplifting.

I was the pusher of the group not the brains. If we did not work as a group this project would have been abandoned at the very start. The friendships that occurred as a result of the project I feel will be long lasting.

With regard to learning about the results and the users who were interviewed I was humbled. Their insight to their mental problem, the way they survive emotionally, financial etc. is amazing. No average person could put up with their endurance.

Knowing that we achieved pioneer work and this research is being used by other groups as a basis for research even before it is published is heart warming.

<div align="center">

Pathways
By Sean C

I thought my life was over
The original Irish Rover
I hadn't worked for nearly nine years
Mostly because of my own fears
I have a mental illness
This just caused more stress
Then I got a call From Niamh
A offer of a job I couldn't believe
She introduced me to the rest of the Gang
It didn't go off with quite a Bang
We came together once or twice
I found the gang very nice
After fourteen months, we are friends
I hope this will never end
We call ourselves Pathways
Because of the road we took
I hope you give our research a second look

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MARIA'S PATHWAYS EXPERIENCE

When I joined Pathway's. I was excited about the idea of being involved in a project, which could be used as a tool for change in the Mental Health Services.
Ideas are great but the practicalities of the work involved and working in a group was challenging for me.

I wondered if my personality and input fitted into the group, and during a time of family crisis I took the opportunity to leave. But with lots of encouragement and support from the other members, I later returned and saw it through to the end.
I thank all the members for this.

The involvement has been very rewarding and enlightening.

I have learned that I do not have to "fit" into the group but to be part of the group by being myself. Ironically working closely with a group has taught me about the value of individuality. People with life experience have a lot to offer and the expression of that which is unique to them, and valuable.

I'd considered myself a person that is a "thinker" but through this project I have found that "doing" is what brings about motion and reward. Expressing oneself through positive action is empowering and not doing something because you may not be that great at it is stifling, "Just Do It"

I have learned to value new or different experience just for the sake of it.

I admire Niamh and Helen for having the "courage of their convictions" and all the members for their strength and honesty.

Frances Pathways Route

When I joined the pathways team, I was unsure what to expect. I can now say with certainty that, at the end of the project, I have gained far more than I could ever have foreseen.

Working as part of a team on such an in-depth project has certainly been a challenge, but the rewards have made it all worthwhile. I will always be grateful to the other team members for their friendship and support, which have meant a lot right from the beginning. Thanks also to Helen and Niamh who gave us their full support and commitment from the outset.

Taking part in this project has, for me, been an enlightening experience. Sharing the experiences of others has made me more accepting of my own involvement with the West Galway Mental Health Services and of my whole experience with my illness.

At this stage, I can say that I am glad that this report happened. I am glad to have been a part of it. I am very glad that we have seen scope for possible change within the service. I hope that others will feel likewise.

Liz's note

I joined Pathways after a long history of involvement with the West Galway Mental Health services, and found the experience to be extremely empowering and liberating. The process of "Mapping our Pathways" allowed me a chance to examine my own history with the service, to hear what others had experienced, and to deal with, and process, the anger, sadness, and loss in my life that were consequences of my illness.

I found working with the others in the team to be both challenging, and extremely rewarding. I feel like I've made friendships that will last a lifetime. I believe, from feedback I've got, that I was like the "anchor" for the group and one of the voices of reason and calm in the project.

I feel extremely grateful to our respondents for sharing their stories with us, and completing the extremely long and involved questionnaire. It is as much a tribute to them, as to the team, that we have the final report and recommendations. I sincerely hope that this project will have some impact, and influence some changes in the service we all use, and make it more user-friendly.

I also think a word of thanks and appreciation is due to Niamh and Helen for their vision and support, which was way above and beyond the call of duty.

Helen: Personal Note

One of the team recently wondered if the facilitators' (Niamh and I) attitudes to the team had changed since the project began. This question gave me food for thought. My honest response is that my attitudes have not changed. I have been in awe of, but not surprised by, the generosity, humour, determination, ability to learn new skills and adapt to new ways of working, to face difficulties, overcome obstacles and persevere demonstrated by the core group. If anything, I queried the extent to which I could match the commitment and determination shown by the team.

Why should I be surprised? I believe that all each of us needs is people to believe in us. We need this because it allows us to believe in ourselves. This step toward self belief can be a most difficult one to take, as we saw at times during the project, but one from which there is no going back.

What I found challenging:
- Uncertainty: the huge uncertainty involved in bringing the project to life and giving it its initial shape was stressful. This required a leap of faith; required trusting that the most effective way forward would naturally evolve as the right

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individuals self-selected onto the project. In other words, Niamh and I closed our eyes, held our breath and jumped. We landed in a better place than we could have dreamed.

- Group research: the process involved a continual striving for consensus decisions on each and every aspect of the project from what to call it to how best to deal with the qualitative data to the font size on the final document and much in between. While this was highly challenging at times, given peoples' vastly different working styles and personalities, it was necessary since the group approach was an intrinsic to the ethos of the project from the outset.
- Juggling: balancing Pathways involvement with the not inconsiderable demands of other aspects of my work proved difficult at times.
- Resource issues: people, time, money, and expertise. These were an ongoing concern over the life of the project. At a critical period towards the end of our (1st!) deadline, the team was reduced to three. Balancing a huge workload with little time, people or funds proved a challenge to all of us. The group provided huge support and energy and combated the isolation often associated with research so when numbers dwindled it became much more difficult to maintain the high levels of energy and enthusiasm needed to complete the project.

What I found rewarding:
- The excitement and satisfaction I felt at being a part of this groundbreaking and long overdue user-led initiative
- The huge sense of achievement at reaching our goals
- The opportunity to meet, work with, get to know and learn from each member of the team
- The laughter
- The support and friendship

What I learned:
- That a cohesive group is a powerful force for change
- That peer support and self-belief can transform
- That anything is possible!

The past eighteen months with Pathways has been exciting, challenging and frustrating in turn but ultimately hugely rewarding. I am thankful for the opportunity to work with each person involved. It has been a privilege. Lets hope it is just the start….

Faith consists in believing what reason does not believe…It is enough for a thing to be possible for it to be believed. Voltaire.

Niamh

Before beginning the pathways project I had lost faith in the system, was losing faith in myself, and was beginning to doubt what once was my firm belief in recovery. This project has been the most exhausting, infuriating, exciting and illuminating work I have ever been part of. We have all recovered in the process. I am proud to be part of a service that was open and imaginative to try something so untried and untested. I am proud of myself for moving way outside the comfort zone my staff role usually protects. But most of all I am proud to be part of a group that has forced me to challenge my attitudes assumptions and supposed expertise. A group that has done absolutely everything the hard way, but has battled on to emerge fifteen months later worse for wear but still interested, involved and connected with each other.

Thank You

We wish to pay particular tribute to Geraldine Flannery, Senior Community OT, who worked with us on the project for months, and then moved into another area of work.

We have to acknowledge the input from several other members, who left before we completed the project, but whose help was vital in different ways. People like Dymphna Laura, Mary-Rose, Jackie, Elaine and Angela.

But two people were particularly influential in shaping the overall result; Ann, who was our chairperson for most of the project, and kept us focused and orientated during long and tedious meetings, and finally Sean S who gave us the benefit of his long experience in social science research and shaped a most important first draft of our report.

Thanks to you all for your contribution, it was particularly appreciated.

Introduction

Introduction

'When people not used to speaking out are heard by people not used to listening, then real changes can be made.' (John O'Brien)

This is an introduction to Pathways, a Service User-Led Survey of People's Experiences of West Galway Mental Health Service in 2000. This introduction will set out the reasons why this project was necessary and how we did it.

"**Very few mental health services in Ireland are truly innovative or willing to attempt new approaches to delivering mental health care**." (Report of the Inspector of Mental Hospitals, 2000)

WHY IS INNOVATION NECESSARY?

Innovation in mental health services is as essential today as it was 20 years ago, and as it will be in 20 years' time. According to Professor Shalumit Ramon there are a number of reasons for this:

- Our evolving understanding of what mental illness and health are about.
- The degree of awareness and assertiveness of the different stakeholders,
- The fact that we operate within a high margin of uncertainty in the context of mental health
- While intentional abuse by service providers is rare, unintentional neglect and disrespect are still affecting users and carers.
- The high – and negative – profile of mental illness in the media, coupled with the politicians' preoccupation with issues of safety at the expense of therapeutic and integrative approaches.
- NIMBY-ism ('Not In My Back Yard') is still riding high in terms of public attitude to people with severe mental illness.
- Social exclusion is rife among people who use mental health services.
- We have hardly begun to look at issues of mental health prevention and promotion, and to consider relevant interventions.

(From: *A Stakeholder's Guide to Innovation in Mental Health Services* (2000). East Sussex, Pavilion.)

The lack of innovation in mental health services may be partially explained by the absence of substantive research to guide and inform new service developments. This was addressed in **Planning for the Future (1984)** which identified various gaps in

information as well as the need for continuing research to provide more definite guidance on norms for service provision ' (16.17, pg 136). Despite recommendations, which are now dated, that a number of studies be carried out, there continues to be a dearth of research into mental health services in this country, from the providers and more particularly users' perspective.

HEALTH STRATEGY 2001

The new health strategy recognises the need to update mental health policy to take account of recent legislative reform, developments in the care and treatment of mental illness and current best practice. The strategy also presupposes people-centred services. This is very much in line with the Declaration of Madrid (1996 WPA) whose dominant theme is the need for psychiatrists to respect the service user and arrive at treatment decisions in collaboration with him or her.

USER INVOLVEMENT IN SERVICE PLANNING

The user/ consumer movement began in the early seventies in the United States when groups of psychiatric patients got together to explore the difficulties experienced by psychiatric patients both in society and the institutions set up to treat them. Two of the main issues identified by these groups were the need for a more holistic approach to treatment and the need for more collaboration between those receiving treatment and those providing it. These issues continue to be a challenge in today's mental health services.

Much international research now acknowledges the importance of user involvement in the evaluation of any service. Pablo, as early as 1975, stated that patient satisfaction could be used as the basis for evaluating whether a given institution has been effective in achieving its goals. He states that satisfaction surveys need to incorporate the users as well as the providers' points of view, thus reflecting service users as active participants, rather than passive recipients in their treatment or care.

There is growing acceptance that differences can exist between service users and service providers' perceptions of a service. The Audit Commission (UK) stated that '…*Listening to users is important if professionals and service managers are to avoid falling into the trap of making assumptions on other peoples behalf, since those views often differ widely from those of users'*.

In other countries, the concept of collaboration with service users is becoming an integral part of service management. According to Gibson (1991) health service, administrators and personnel are specifically required to consult with users and carers in the planning and development of services. This movement is well established in America and Britain. Consumer/survivors and mental health professionals forming working partnerships are developing new models of care. (Van Tosh 1993).

Bassman (1997) suggests that there is no one as expert on what has helped or hurt as the people who have personal experience of services. He also states " *The knowledge gained from patients personal experience can provide a rich resource for everyone who attempts to aid individuals in the struggle to deal with these painful life circumstances.*"

In 1998, the World Health Organisation described empowerment and participation as key principles of health promotion. They define empowerment as "*enabling individuals and communities to assume more power over the personal, socio-economic and environmental factors that affect their health.*" In this region, the report **Promoting Health in the West** (1999) stated that these principles mean " *we respect the way people choose to live their lives and we involve people in the planning and delivery of services.*"

The experience of mental health problems does not preclude a rational balanced view about issues such as services on offer and their acceptability to those who use them. The significance of consulting the views of MHSUs lies within the ethos of community care in which the aim is to place service users (and user-defined outcomes) at the centre of service development and to create the conditions in which service users can be empowered to say what they believe will improve the quality of their lives.

Pathways

Given the lack of current research and policy on which to base future service development and the belief held by the coordinbators of this project, namely that any development must place users views at the centre, we sought funding from the WHB to set up a research project carried out by service users and about service users. This project became Pathways.

We believe that when people not used to listening hear people not used to speaking out, then real changes can be made. These changes are to be found within the system and within the individual. We hoped that this project would instill hope into the individuals involved whilst accepting challenges and promoting strengths.

AIMS
The aims of this project were twofold:
⊄# To facilitate empowerment of service users
⊄# To evaluate existing services and inform future developments

In the absence of existing research the Western Health Board are to be congratulated for their willingness to fund this new and innovative project. This implies an acceptance of the need to place service users at the centre of service development and willingness to embrace change and engage with people who have traditionally been excluded and voiceless. This is the first research of its kind in the Western Health Board and indeed in this country. A truly innovative aspect of the research has been the board's willingness to enable users of the service to decide for themselves how this research should be designed, conducted and presented.

HOW DID WE DO IT?

Once we established what needed to be done (exploratory survey of users' experiences of the services) and who should do it (service users), we then needed to decide upon the most suitable research approach. After a trawl of the literature on models of action research, we discovered a method of investigation that involves users of the service in all aspects of the study and acknowledges the participants as having ownership of the research. This approach is known as Participatory Action Research (PAR).

PAR is a scientific paradigm most relevant for inquiry and action with user-led groups. Two of the main hallmarks of participatory action research are subjects' individual and collective involvement in the design, conduct and utilisation of research and scientists' involvement in action to improve group functioning.
(Chesler MA, 1991, 'PAR with Self-Help Groups: An alternative paradigm for inquiry and action', *American Journal of Community Psychology, Oct., 19 (5), pp. 757-768*)

GOALS OF PARTICIPATORY ACTION RESEARCH

PAR epitomises four main research goals:
1. Empowerment;
2. Supportive relationships;
3. Social change;
4. Learning as an on-going process.
(Nelson G., Ochocka J., Griffin K. & Lord J., 1998, 'Nothing About Me Without Me: PAR with self-help, mutual-aid organisations for psychiatric consumers / survivors'. *American Journal of Community Psychology, Dec. 26 (6), pp. 881-912).*

Morrell-Bellai & Boydell (1994) examined the experiences of six mental health consumers who were involved in paid employment as researchers in the mental health field by conducting semi-structured interviews in order to identify any benefits experienced because of their employment and any special needs that should be considered when employing consumers.

Their paper supported both the benefits experienced by mental health consumers who are employed as researchers and the necessity of providing meaningful opportunities for them to give feedback on their experiences. (Morrell-Bellai T.L. & Boydell, K.M. (1994). The Experience of Mental Health Consumers as Researchers. *Canadian Journal of Community Mental Health*, *13 (1), pp. 97-110)*

White (1989) gives an interesting account of the personal experiences of consumer participation within the Canadian Mental Health Association. (White, J.C. 1989. *Consumer Participation: A personal journey. Canadian Mental Health, 37 (2), pp. 2-4).* He states that the whole plethora of committees, boards and other groups can encourage

user collaboration by accepting and supporting such individuals and groups because they bring a personal, untainted, passionate knowledge of both the problems and potential solutions. In other words, partnerships among users, professionals, family members and community activists can and will increase effectiveness.

PEER SUPPORT
However, White pointed out those users who identify themselves and participate face 'financial and emotional costs' because it is their 'anger with the system' that motivates them to try to create change. There are those with a vested (professional, ideological, financial) interest in maintaining the status quo. People taking such risks need both practical and emotional support. Other group members can help provide the safety that makes user participation possible.

Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful. (Mead, S., Hilton, D. & Curtis, L. (2001). Peer Support: A Theoretical Perspective. *Psychiatric Rehabilitation Journal, 25, 2.* Peer support is not based on illness labels but can provice a culture of health and ability.

A participatory action research approach relying on a built-in support mechanism emerged as the most effective approach to the current project. Respect, shared responsibility and mutual agreement became the principles upon which the Pathways team progressed. This was one of the main rationales behind the regular 'support group meetings' held by the research team throughout the exercise. This support group focused on the members' perceptive experiences of their participation in the project and ways in which these influenced – for good or ill – their lives and particularly their own mental health.

For this type of project to work, we recognised early on that all those involved must be willing to accept and promote the possibility of recovery for themselves and for others.

BRINGING THE RECOVERY CONCEPT TO LIFE
The recovery vision emerged against a background of important psychiatric studies of the long-term outcome of schizophrenia (Harding, C., Zubin, J., & Strauss, J. (1992). Chronicity in schizophrenia: Revisited. *British Journal of Psychiatry*, (161) 18, 27-37. This and similar studies defined recovery as the absence of current signs or symptoms of mental illness, no medication, and lack of social and vocational dysfunction. After 32 yrs of follow-up, 2/3 of a group of severely disabled long-stay service users had significantly improved or recovered despite seemingly bleak prospects years earlier.

These findings strongly suggested for the first time that people with severe mental illness are much more likely to recover than was thought possible in the past. By the early 1990's, William Anthony began urging that the idea of facilitating recovery be adopted as the guiding vision for mental health services and research (Anthony, W. 1993. *Recovery from Mental Illness: The guiding vision of the mental health service system in the 1990's.* Psychosocial Rehabilitation Journal, 16,4 11 23.)

Although recovery is accepted as a familiar concept in physical illness and disability, it has traditionally been viewed as a radical idea in mental health. Anthony (1993) states that recovery is a deeply personal unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. He goes on to explain that people with mental health problems may have to recover from the stigma they have incorporated into their lives, from lack of opportunities for self-determination, from the negative side effects of unemployment and from crushed dreams.

FACTORS INFLUENCING RECOVERY

Factors influencing recovery are variable with some common themes emerging from recovery literature as follows:

- Being believed in and encouraged by at least one other person who believes progress and change are possible
- Developing perspective on the past including grieving over what is lost
- Taking personal responsibility for one's life for example identifying preferred and unacceptable forms of treatment
- Acting to rebuild one's life
- Developing valued relationships and roles i.e. a support system
- Changing other people expectations of what one can achieve i.e. resisting an identity dominated by an illness model
- Gradually gaining a sense of greater well-being and contentment
- Developing new meaning and purpose in life including accepting personal limitations

And finally,

- Persevering through pain, struggle, symptoms, setbacks with an acknowledgement that recovery is not a linear process

(From Turner-Crowson, J. & Wallcraft, and J. 2002. The Recovery Vision For Mental Health Services and Research: A British Perspective. *Psychiatric Rehabilitation Journal, 25, 3.*)

It is widely accepted, that the provision of a mental health service involves more than the alleviation of psychiatric symptoms. The challenge involved in addressing the social, economic, vocational, emotional and spiritual needs that impact people's mental health now requires a more creative response from service providers. If we believe that people support what they help to create (Beckhard), we should view users of the mental health services not as passive recipients of treatment but as active involved participants in their treatment. This approach will provide valuable insights in the development and delivery of services. "For the survivor/ activist, there are no outside experts who can understand better what has helped and what has hurt than the people who have been there. " (Bassman, 1997 pg.239).

Services that are adopting a user inclusive approach are acknowledging the expertise service users have gained from their experience of illness and recovery, and using this expertise to identify the increasingly complex needs of people using their services.

The knowledge gleaned from consumers/survivors personal experiences can provide a rich resource for everyone who attempts to aid individuals in the struggle to deal with these painful life circumstances. (Bassman, 1997)

THE WAY FORWARD

The vision of our new health strategy is of:
"A health system that supports and empowers you, your family and community to achieve your full potential;
A health system that is there when you need it, that is fair, and that you can trust;
A health system that encourages you to have your say, listens to you, and ensures that your views are taken into account".

Regarding the mental health care system, there is recognition of the need to update mental health policy. In light of this national vision for the future development of our health service, and bearing in mind the objective of placing the service user at the centre in the delivery of care, this research is therefore both innovative and timely and takes a large step toward the achievement of these welcome goals.

METHODOLOGY

Background

This project originated out of a perceived need for an investigation of users experiences of the of mental health services in the Galway city area. It explores the experiences of 51 service users in West Galway. It was agreed that a participatory action research approach should be adopted. A process called 'Mapping our Pathways' generated a questionnaire.

The research team members were sourced through personal contacts by members of staff, and word of mouth from other users. The criteria for inclusion were simple, people who had used the mental health services and were willing to commit time and energy to the project. The groups' experiences varied from limited outpatient contact with the service to many and long, inpatient stays in an acute unit

Design of Questionnaire by Group Process

Initially, because the team had no specific brief in terms of defining the research, there was a lot of anxiety in attempting to draw up a research proposal. It was decided to compare and contrast the different experiences of individual group members in an attempt to identify the points of concurrence and departure. The service users on the research team met as a group to explore their own experiences and constructed the questionnaire around emerging themes. This process was referred to as "mapping our pathways".

The group met once a week with a facilitator on the team for a support group session to maintain the group as the members went through the process of examining past experiences of the services. This was an important part of the process because of the personal, and often painful, nature of the experiences, and also for the group bonding together as an effective research team. The members began to very much own this sharing of memories and the issues that emerged. These issues eventually evolved into the individual sections in the questionnaire.

Although it was acknowledged that the questionnaire was very long, it was not considered appropriate to omit any section because the team wanted to ensure that the experiences of every member played an important and equal role in defining the terms of reference and coverage of the investigation. Perhaps this evolved into a weakness in the methodology, but such a price was acceptable to the team given the achievement of a participatory, democratic, egalitarian research team.

Pilot Survey

An initial survey was carried out to test our questionnaire. This consisted of interviewing 15 people who were contacted by members of the team and who agreed to participate. Following this refining stage, we developed the final questionnaire.

Selection of Participants for Final Survey

A random sample of 300 names was selected by the West Galway Mental Health Service staff on the team who went through the database of names of users who had attended the service, either as in-patients or outpatients, during the period June to December 2000. A consent form was sent to these 300 people and they were asked to return this if they were willing to participate in the project. Only once the signed consent forms were returned did the research team get access to their names. About 80 consent forms were returned out of a total of 300 (a response rate of 26.7%).

Interviews

Appointments were made and the interviews conducted during the month of August 2001. A weekend was set-aside in the Day Hospital facility and over 35 interviews were conducted this weekend. However only about half the people expected turned up and individual appointments were made later for some of these people. The remainder were made up by personal contacts. The team had some training in interview techniques from Ewen Speed, Department of Sociology, Trinity College Dublin, a research consultant to the group.

Questionnaire

 The final questionnaire included the following sections:
1. **Demographics**:- this was included to develop a profile of the participants and their socio-economic circumstances
2. **First Contact with the Service**:- during the "mapping the pathways" process, we found that first contact with the Mental Health Service was traumatic. For some it was a positive experience, while for others it was very negative. The team wanted to get an overall picture of users' first impressions of the services. We also wanted to determine accessibility of the services - e.g., one member was paying for private treatment for nine years before she found out about public services.
3. **Diagnosis**:- this was a major event for everyone in Pathways. The manner in which diagnosis was handled by doctors and the length of time taken to communicate it to the user emerged as issues to be addressed in the exercise. There was consensus that the labelling of mental illness is both stressful and disturbing.
4. **Contact with Professionals:-** this was included as the manner in which professionals relate to users is very important for the prospect of progress. There was a collective experience of a distinct power imbalance with most of the professionals in MHS and it was agreed that this should be addressed by the sample.

5. **Medication**:- the group found that medication was used as the primary treatment by the medical staff. It was also agreed that negative side effects were common and that patients were not usually informed about these.
6. **Electro-Convulsive Therapy**:- this treatment is offered in conjunction with medication and we wanted to review the users' experiences of it.
7. **Counselling/ Talking Therapy**:- the team decided to include the area of counselling/talking therapy in the questionnaire as a proposed alternative in the services to medication or ECT.
8. **Privacy**:- for some of the group this was a big issue, as some mental health conditions require high levels of privacy.
9. **Activities in the Psychiatric Unit**:- this is a provision that all members of the team availed of, as activities in the Psychiatric Unit form a major part of the day's struggle to overcome boredom. It was agreed to investigate any beneficial nature of these activities and look for the users' ideas on modes of improvement.
10. **Preparation for Discharge/Aftercare:-** some of the group found that there was good preparation for discharge including day and week-end leave, while others found this lacking. All agreed that aftercare was inadequate and needed to be addressed.
11. **Crisis while in the Unit:-** this was included because some of the team had experiences of major problems with crisis management in the unit.
12. **Crisis outside the Unit:-** for the majority of the group the only place to go in a crisis, outside office hours, was casualty, and this was felt to be inadequate, counter-productive and totally inappropriate.
13. **Activities in the Day Hospital:-** it was important to assess how effective and beneficial activities were in the Day Hospital, as these form a major provision area for recovery and, indeed, day-to-day agenda for users.
14. **Day Centres:-** it was agreed to introduce a section on Day Centres because those of the group who attended found these lacking as a form of aftercare support.
15. **Training Centres:-** all of the group thought that training was very important for recovery and employment prospects and it was important to evaluate the effectiveness of the various training centres.
16. **Employment:-** no members of the user group were in full-time employment. This section was planned to explore the difficulties experienced with jobs and employers. It was agreed to examine the support offered to users to find suitable employment and any perceived discrimination against people with mental health problems.
17. **Well-being:-** this section was included to investigate the coping mechanisms employed by users with their illness. The user group found that isolation and stigma were highly negative influences on their recovery and it was pertinent to investigate how users managed these problems and their perceptions of the potential for improvement in services to deal with these devastating experiences.
18. **Housing:-** adequate housing and homelessness was an issue for the core group as most had known some users who were homeless leaving the unit. Surviving on a low income, financial and other material insecurities due to illness and the fear of never having a proper home of one's own were identified as common experiences of many users of the Mental Health Services.

Interpretation of Data

Questions attracted both quantitative and qualitative data. The quantitative data were analysed using SPSS. It was agreed that the open-ended questions should be incorporated in order to capture the reality of users' subjective, lived experiences. These were categorised to make them more manageable.

Presentation and Dissemination of the Results

It was planned that the research team would publish a report on the findings of the investigation and publicize the report at a launch at a venue in Galway city. Copies of the report would be available to all interested groups, agencies and individuals and the team would ensure maximum public awareness of the results.

Chapter One

Demographics

And

First Contact with Services

Demographics

Introduction

We included this section in order to get a profile of our sample, to get some idea of their ages, how long they have been involved with the services, working and marital status, etc.

Main Findings

Length of contact with Services, age now, and at first contact

- 56% of respondents have been involved for more than 5 years
- 46% for more than 10 years

Figure 1 Length of contact
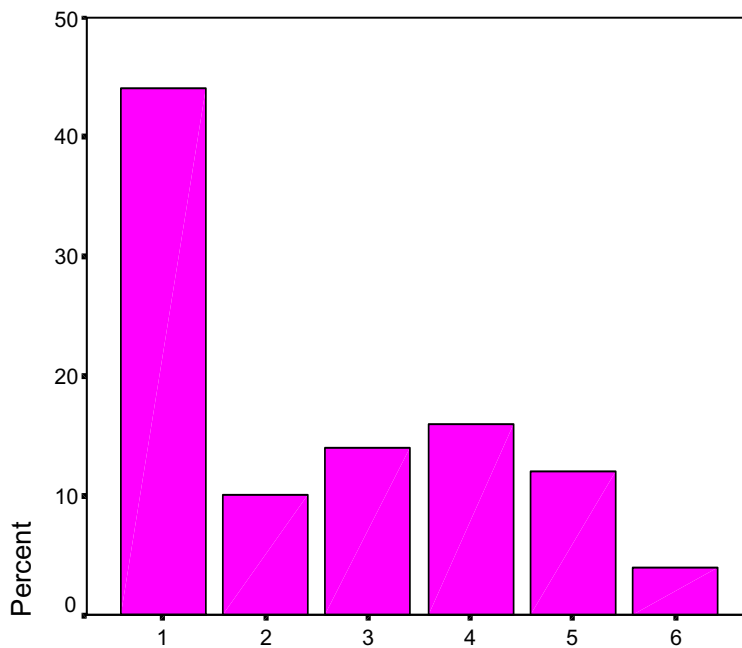
Ranges	Years
1	1-5
2	6-10
3	11-15
4	16-20
5	21-25
6	Over 25 yrs

- 45.1% are aged under 35
- 74.5% are aged under 45
- only 11% are aged over 56

Figure 2 Present Age
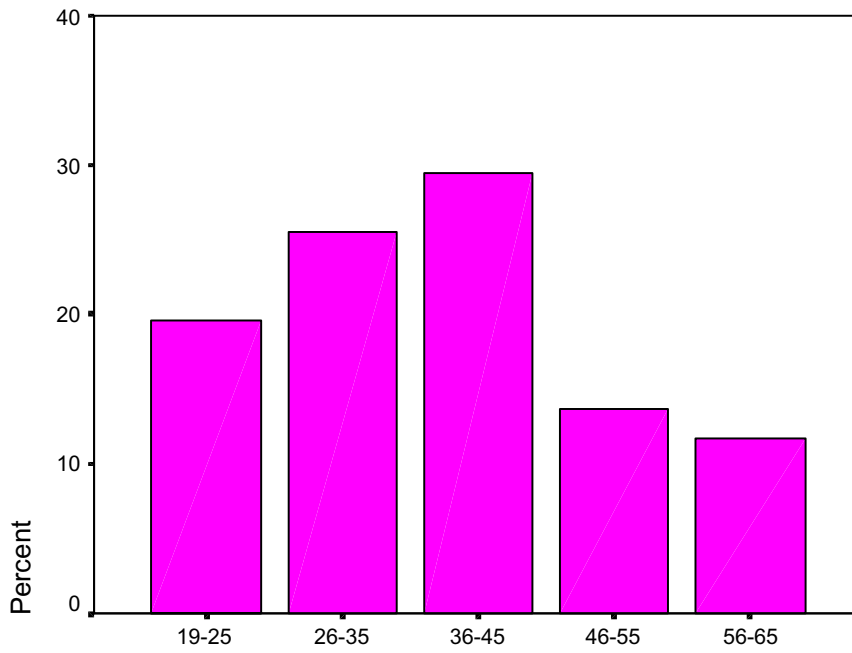
⊄# A majority (59.2%) were aged under 25 at first contact

Figure 3 Age at First Contact
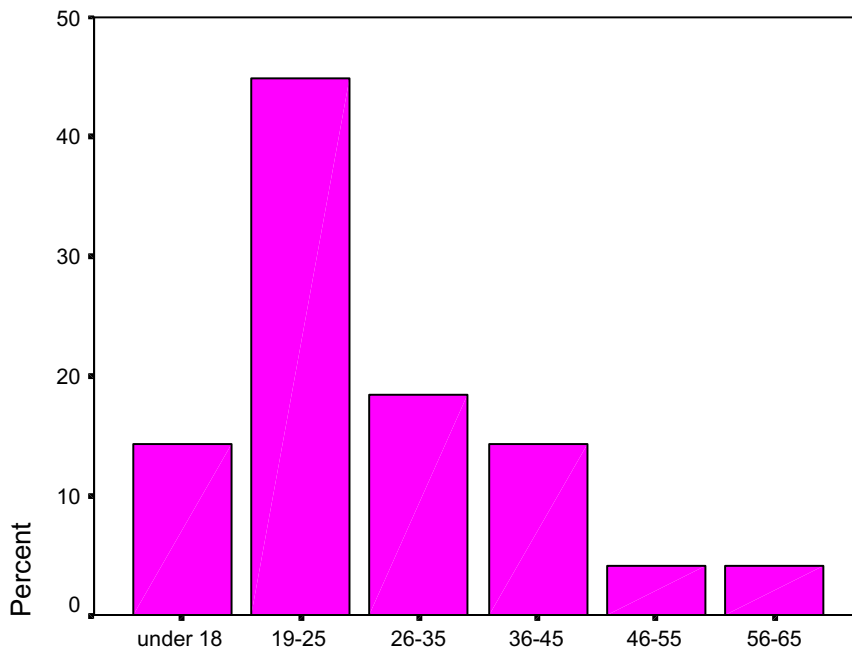
Gender, Marital Status and Living Situation

We found gender to be almost evenly distributed,

  ∉# 49% male,

  ∉# 51% female

Marital status revealed an interesting finding in that

  ∉# a substantial majority (80.4%) were either single, widowed, separated or divorced.

Figure 4 Marital Status
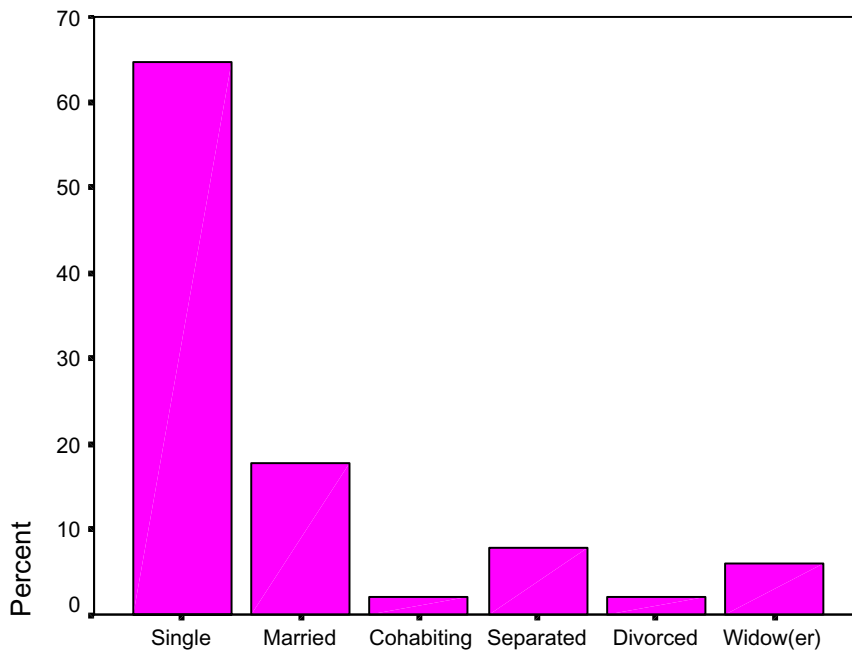
  ∉# a substantial minority (30%) were living alone

  ∉# also another substantial minority (28%) were living with parents

Figure 5 Living Sitution

Figure 5 Living Sitution
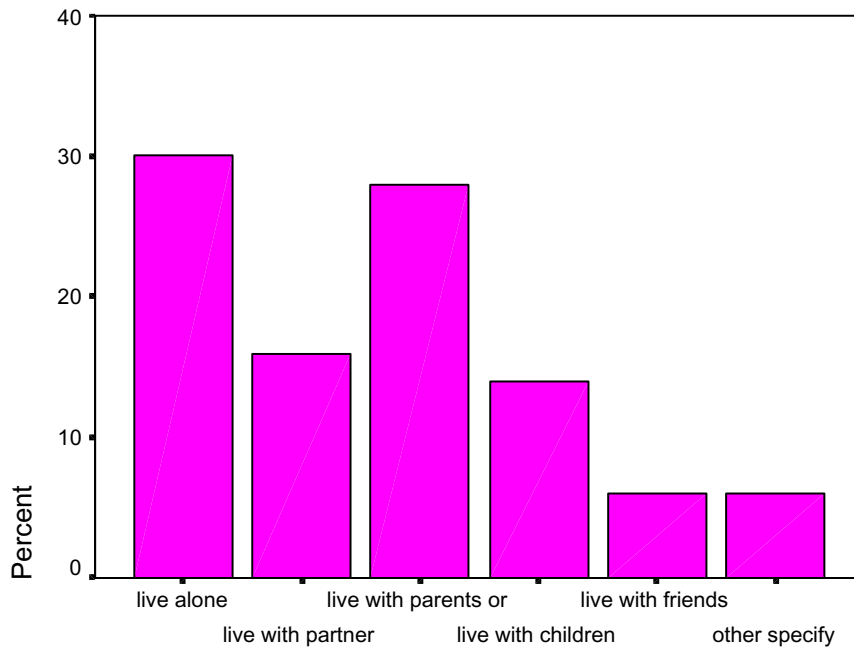
Employment Status, and Social Welfare Payments

Figure 6 Working Status

Figure 6 Working Status
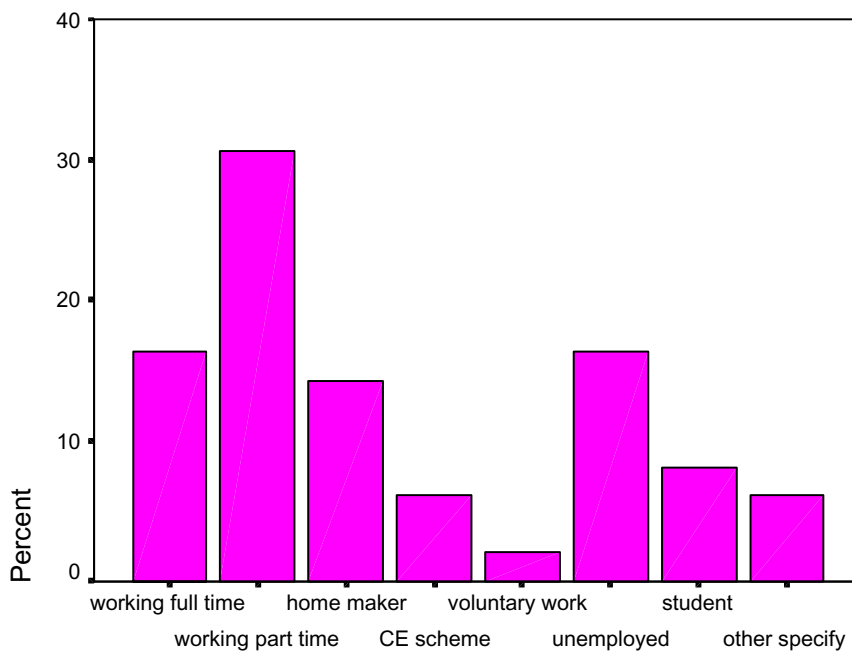
⊄# 16.% were unemployed, compared with the national average of 3.5%

⊄# only 16.3% were in full-time employment

⊄# the biggest category was those in part-time employment (30.6%)

were in receipt of social welfare benefits
32% were not
Of the above 68%, 69.4% were in receipt of Disability Allowance/Benefit.

Figure 7 Type of Social Welfare
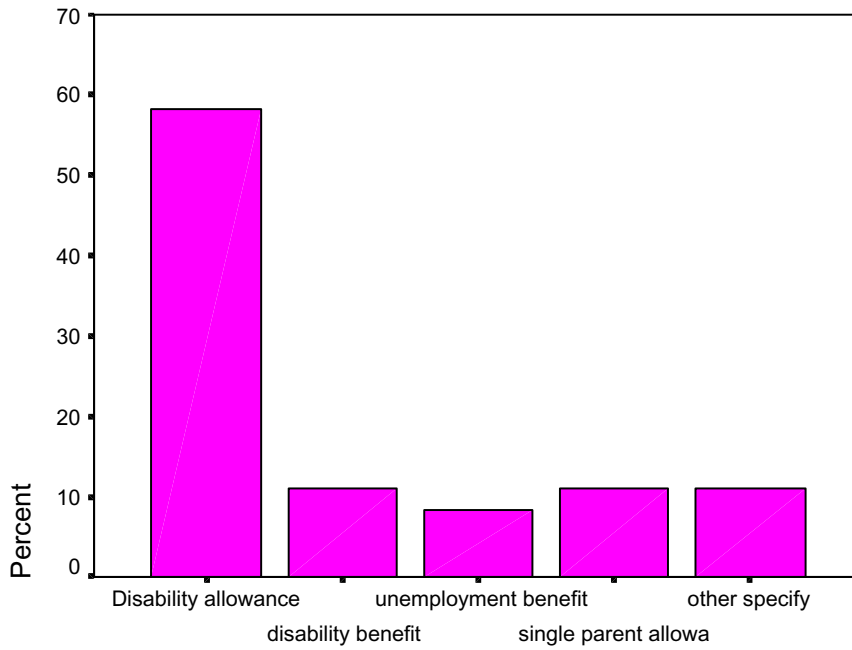
Discussion

It is interesting to note that contact with the West Galway Mental Health Services among the sample is very lengthy, raising the question of whether this is due to the effectiveness of interventions by the services, or the long-term nature of mental health problems. This contact (and indeed, the onset of mental illness) appears to start early in the lifespan – almost 60% were aged under 25 when they first had contact with the services. The main concern is that mental illness can occur when younger people have most to look forward to and have the greatest potential contribution to make to society. More importantly, this is a time that is crucial in the formation of identity, in choosing a career path and in forming relationships, and anything that interferes with this process of formation may have serious consequences for the emerging adult.

The marital status of respondents generated an interesting finding – over 80% described themselves as being single, widowed, separated or divorced (64% were "single"). This may be a reflection of the fact that a quarter of those surveyed were under 25, or of how mental health problems may impact on intimate relationships.

Gender was evenly distributed among the sample, but there was a clear over – representation of the unemployed (16.3% compared with a national average of 3.5%), and part-time workers (30.6%). A further 14.3% claimed homemaker status; 8.2% were students; 6.1% were on CE schemes; 2% were doing voluntary work – so in effect 39% were not in paid employment. The issue of "cause and effect" is relevant here – are unemployment and underemployment causal factors in mental illness or, are they by-products of mental health problems?

Related to this are the levels of dependency on welfare benefits paid to the poorest sections of the population – 2/3 of the sample were in receipt of welfare benefits and almost 70% of these were in receipt of Disability Allowance/Benefit. This is significant in light of the fact that people on disability allowance are deemed unable to work, and also are often caught in a poverty trap. This in turn may have an impact on mental health.

This section presents some interesting issues from our sample group, which would be worthy of further research, to explore the impact of socio-economic factors, relationships and employment on mental health.

First Contact with the Services

Introduction

This section was included because we wanted to get a picture of users' experiences of their first contact with the services, as we felt that this was an important event in people's history of involvement with the mental health services.

Main Findings

Length of time ill before contact, source of referral and part of service first attended

- 28% were ill between 1 to 5 years before coming into contact with the mental health services.

"So afraid, I fought it big-time"

- 26% were ill between 5 to 10 years

"I was very fearful before I used the service, I was afraid I would be locked up forever. I was sick for months before I got help."

- Perhaps reassuringly, 30% were ill less than 6 months
- The majority (53%) were referred by a GP
- 63.3% were admitted to the Mental health Unit
- 36.7% attended Out-patients

Feelings of fearfulness and reassurance given

- 59% reported feeling fearful of using the services, while 40.8% did not

Reasons given for feelings

"Thought they were there to help me"
"No, I felt I needed a place to go"
"Worked in hospital, so afraid of their reaction to me as a member of staff. People's opinion, is still there."
"I saw it as a refuge"
"I had a feeling that someone with worse problems might attack me"
"When I'm ill I'm not afraid, when well I am"
"Yes, afraid of being in hospital, fear of the place, fear of not getting out"

- 58.3% found their first contact reassuring, while 41.7% did not

28

Reasons given

"I felt lonely and isolated, also don't think I was given the right medication"
"I was very ill at the time, the staff were very reassuring"
"Most of the staff were grand, but some had no understanding. I experienced bullying by some of the staff, even though I was ill I recognized it. I still remember it"
"Very warm and welcoming. Very reassuring."
"No, being a traveller, and not well educated, I found the words they were using hard to understand. They were very nice though, five star"
"No, I wanted someone to tell me I'd get better, nobody did"
"Yes, I was put at ease by the doctor"

Who accompanied person, and treatments offered

- 51% were accompanied by either a partner or family
- 36.7% went alone
- 82.4% were prescribed medication
- 45.1% were admitted to the Unit
- 11.9% were offered talking therapy
- 3.9% were referred to another professional
- 3.9% refused treatment offered

People were offered more than one treatment

Communication with users and their families around illness and treatment

- 70.5% said their illness was not discussed adequately with them

"I feel my doctor didn't devote adequate time to talk to me and I should have been offered counseling from a psychologist"

- 40.4% said their family was given an opportunity to discuss their illness, while 51.1% said their family was not given this opportunity

"My parents were told nothing"
"My father died on my first visit, my husband wanted to talk to somebody about whether to tell me or not. He couldn't get to talk to them. He was very disappointed"

- 33.3% said their treatment programme was adequately discussed with them, while 66.7% said it was not

"Nobody reassured me re recovery. Even recovery over time"
"I know there is a much better service now than there was then. I wouldn't automatically be given E.C.T. after an overdose now hopefully."

- ⊄# 32.6% said their treatment programme was adequately discussed with their family, while 67.4% said it was not
- ⊄# 17.6% said they were involved in planning their own treatment, while 82.4% said they were not

Discussion

55% of those surveyed said that they were ill for more than a year before contacting the Mental Health Service and 30% were ill for more than five years. Why do ill people wait so long before accessing the Mental Health Service? In *Promoting Health in the West 2001, Dept. of Public Health, WHB,* the vast majority of the sample stated that they would use the Mental Health Service- but only if circumstances were extreme (e.g. total breakdown). If we assume that mental illness deteriorates without medical intervention, then many mildly ill people may become acutely ill by the time they access the services.

Another major finding was the feelings people reported about first contact with the Mental Health Service; almost 60% were "fearful", (of being "locked up", of medication, of other patients, of the stigma of being labeled mentally ill). Although the majority (58.3%) felt reassured by contact with the service, a substantial proportion (41.7%) were not reassured. This finding should be looked at by the service providers, as people who were fearful did not always have their fears allayed by their first contact with the service. Another disturbing finding is the number of people who went alone, (36.7%) on their first contact with the services. Given the general feelings of fearfulness reported, it is alarming that so many people had to go alone, without the support of family or friends.

The issue of communication, about both illness and treatment programmes, between service providers and service users, and their families, is another significant finding. 70.5% believed their illness was not discussed adequately with them, and 51.1% said their family was not given an opportunity to discuss the users' illness. Also 66.7% reported that their treatment programme was not adequately discussed with them, and 67.4% said this was not discussed with their family. While almost 20% said they were involved in planning their own treatment, a far greater proportion, (82.4%) said they had no involvement or input into their own treatment plan.

It is particularly interesting that so many users should report inadequate discussion of both their illness and treatment, and involvement in planning treatment, especially when an international professional body, The World Mental health Association, clearly states that service users should be involved and informed about their treatments. *(Declaration of Madrid, WPA 198-)*

The communication relationship between service users, carers, and service providers should not be just a clinical provision of information by the "expert" to the user in an inappropriate and disempowering environment. Dr Ian Daly, Consultant Psychiatrist, argued at the *Schizophrenia Conference 2000* that "just imparting the information means almost nothing because really the long-term issues are these journeys of knowledge and

emotional discovery". He proposed a more user-friendly arrangement in which consultations take place in the home rather than in a clinic, thereby empowering the user and family.

Recommendations

1. There should be a concerted effort by the mental health services to address the perceptions of mental health problems in the general public, using educational and promotional programmes, so that the issue of the stigma of mental illness and fear of the service is challenged and removed.

2. People should be encouraged to access the services earlier, by above-mentioned educational and promotional programmes.

3. There should be a clear policy of actively reassuring users on their first contact with the services.

4. There should be much better communication between users and service providers.

5. In particular, more information about their illness, and recovery prospects, should be given to users, and their families.

6. Users should also be consulted about their treatment programme, and be given the opportunity to have an input into this.

7. Consideration should be given to having a user-friendlier environment for consultations between professionals and users, in particular for initial contact.

Chapter Two

Treatment

Diagnosis

Medication

ECT

Counselling

Activities in The Unit

Preparation for Discharge

Crisis in the Unit

Contact with Professionals

Privacy

Diagnosis

Introduction:

In this section we were interested in capturing the users experience of receiving a diagnosis and the source of this diagnosis. We were not interested in a specific diagnosis
.

Main Findings:

Source of, and satisfaction with, diagnosis.

❏ When asked about the initial source of their diagnosis, a variety of qualitative responses fell into the following categories:

On a form	8%
G.P	26%
Psychiatrist	22%
Self Education	10%

" It was explained by my GP"
" First admission to hospital, didn't know. Found out my diagnosis by sickness certificate"
" When I got home it was written on a form"
" From psychiatrist as out-patient"

❏ When asked about satisfaction with the source of their diagnosis:

55.3% responded that they were satisfied.
29.8% responded that they were not.
14.9% responded that they did not know.

"I'd like to know why patients have to go through all this alone, without being told. They've had experience with so many people."

❏ When users were asked if they would like to have more information on their diagnosis:

72.9% said yes they would like more information.
18.9% said no.

" Like to know how they got there"
" Was never explained to me properly about diagnosis"
" They were very vague, not to the point"

Additional Comments

When users were asked if they had anything further to add, comments were as follows:

> *" First diagnosis was wrong and it wasn't explained what was wrong with me."*
> *" I think the doctors must have been right because a second doctor gave me the same diagnosis"*

Discussion:

There was such a diverse range of sources where people found out about their diagnosis that it is apparent there is no formal procedure in operation within the West Galway Mental Health Service for relating diagnosis to the user. The experience of receiving a diagnosis can be a very personal one, depending upon the sensitivity with which it is handled and the understanding of its implications for the user. Users have learned of their diagnosis by such abstract sources as finding out from a sickness certificate, on a form or self diagnosis. 14.9 % of users replied that they did not know whether they were satisfied about how they found out about their diagnosis. This may be due to a lack of expectation by the user or the perception that receipt of diagnosis is a negative experience and therefore the level of satisfaction is difficult to discern.

At the very least, this section should highlight the necessity for the Mental Health Service to handle this issue.

There is a very small amount of information reaching the user as 72.9% of the sample felt that they would like more information on their diagnosis. There was a strong desire among users to understand the personal implications of their diagnosis. Lack of information regarding an illness may lead to a cloud of fear and mystery enveloping that illness. The more informed the user is about the illness, the better they can cope. Support during and follow-up support after diagnosis is necessary to demystify the illness and empower the user.

Through correct management of diagnosis it may in future be perceived as a milestone toward recovery or illness management rather than a wholly negative experience.

Recommendations:

1. Create a safe and supportive environment for addressing the feelings and queries of the user regarding their diagnosis and to ensure users complete understanding of the implications of the diagnosis.

2. Maximize awareness of user understanding of the personal implications of their diagnosis.

3. Relay written information for the user's reference.

4. Follow-up support to be available after diagnosis.

Medication

Introduction:

This section investigates users experiences with prescribed medication and the extent that medication is used as a form of treatment within the Mental Health Services

Main Findings:

Medication Explained

⊄# 98% of the sample were prescribed medication.

⊄# 84% of the sample are currently taking medication.

> *"I don't think the doctors take time to see if the patient really needs medication".*

⊄# 58% responded that medication was not fully explained to the primary carer, partner, parent, friend or advocate.
⊄# 20% responded that it was explained.
⊄# 16% didn't know.

Agreeable to take Medication

⊄# 81.6% were agreeable to take Medication
⊄# 18.4% were not in agreement to take medication.

⊄# Of the 18.4% that were not in agreement:
  ⊄# 33.3% took it after "being reassured".
  ⊄# 44.4% took it after "being pressured".
  ⊄# 22.2% took it after "being physically forced".

⊄# 56% understood why they were taking their particular drug.
⊄# 40% did not understand.

Medication, the Only Option

When people were asked if they thought that medication was the only option at the time, the responses were almost equally divided between yes and no. Most of those that responded with no also believed that counseling/talking therapy should have been offered.

(1) **NO, not the only option** - Talking and Therapy mentioned.

" Therapy would have been helpful".
" I feel I should have been counseled".
" I think that medication does help but it doesn't solve everything since I spent
years learning 'paranoid' skills which I have no to unlearn"
" No, somebody to sit down and talk, I was treated like an animal".

(2) **YES, the only option**.

" Yes it was the only chance I had, my symptoms were acute and distressing and
it seemed to provide the only relief"
"yes, I was very unwell at that time"
"yes, was not in control of things on my own, too ill."

Benefits and Side effects Explained

⊄# 61.7% reported that the benefits of their medication were explained to them.
⊄# 38.3% reported that they were not.

⊄# 40.4% reported that the side effects of their medication were explained to them.
   57.4% reported that they were not.

Knowledge About Medication

When asked where people got their knowledge about their prescribed drug, they
answered

⊄# From Drug Company leaflet	29.4%
⊄# From Consultant Psychiatrist	21.6%
⊄# From G.P	13.7%
⊄# From Duty Doctor	9.8%
⊄# From Books	15.7%
⊄# From Internet.	5.9%
⊄# From Other Patients	2.0%
⊄# From Other	11.8%

Involvement in Planning Medication

⊄# 24.5% reported that they had been involved in planning their medication.

"Need to be careful in prescribing medication, side effects can be bad.

≢ 75.5% reported that they were not involved in planning but would like to have been.

> *"It's very messy the way they deal with it, they never tell you about your options, like new drugs."*

Stopped Medication without Discussion with Doctor

≢ 67.3% of respondents had stopped taking their medication without first discussing it with their doctors.

≢ When asked about their reason for stopping the majority cited side-effects as their reason.

> *" I felt medication was creating symptoms, not (addressing) causes. I don't want to be relying on medication."*
> *" Felt doped all the time".*
> *" Weight gain".*
> *" Didn't suit me, bad side-effects".*
> *" Unable to sleep"*

≢ When users were asked for any other comments on the subject of medication the majority of respondents were concerned about side-effects:

> *" Side-effects were not explained and I felt that they should have been"*
> *" Should go more into side-effects"*
> *" My previous medication had side-effects, it should have been changed sooner"*
> *"I can't function as a normal human being. I'm coming in three times a year anyway. I need to have a life. Normal sleep, its not happening."*

Discussion:

The primary form of treatment offered by the Mental Health Services in pursuit of mental health health is medical drugs. "Today, psychiatric drugs are one of the most widely prescribed of all medicines (Lacey, 1991). Medical drugs aspire to alleviate specific symptoms of an illness and therefore rationally improve the quality of life for the user. If this is so, then why do so many users (67.3%) stop taking their medication without consulting their doctor? There is something very wrong.

Users said that they stopped taking their medication as they often experience bad side effects from medication and so discontinue its use to alleviate their discomfort. The negative experience of side effects would appear to outweigh the benefits of the medication. To further compound the issue many users are not expecting any side effects, as they were uninformed about side - effects. A drug's effectiveness needs

monitoring on an individual basis. Are side-effects taken into account when measuring the effectiveness of a drug?. It would appear that there is a discrepancy in the measure of perceived effectiveness between the system and the user

.Users need to be informed on why a particular medication is prescribed for them, what is the scope of the medication regarding the treatment of their illness and what are the possible side effects. This information will enable users to be aware of what the medication has to offer as a treatment in both its limitations and benefits. Users should have choices regarding medication and be able to make informed choices. Another of these choices would be whether medication is their only option.

Many users in the sample would like to have had counseling or some sort of talk-therapy instead of or in conjunction with medication. This could be seen as a desire on the part of the user to deal with the cause of their illness not just the symptoms. Users would like and should be active participants in their own recovery.

Recommendations

1. Users should be provided with choices regarding medication.

2. System put in place to ensure users are provided with impartial information on all aspects of their prescribed medication, both verbally and written.

3. Users should be fully involved in the planning of their treatment.

4. Other forms of therapy should be explored instead of, or in conjunction with, medication.

5. Review of medication should be carried out on a regular basis.

Introduction

This is a treatment offered to some users as well as medication. As it is a controversial treatment, arousing strong feelings, it was decided to explore users' perceptions of it.

Main Findings

Prescribed ECT

- 36.3% of the sample had been prescribed E.C.T.
- 77.8% of those prescribed E.C.T. had the treatment

> *"Completely went along with it at the time. In the early 70's"*

Agreeable to have treatment

- 71.4% were agreeable to have the prescribed E.C.T.

> *"I would have tried anything as I was very depressed"*
> *"I feel ECT was helpful at the time"*

- of those who were not agreeable initially, 66.7% felt they had been pressured into having it.

> *"I hadn't much say in it, no choice about it"*
> *"I felt I had no choice"*

Understanding of reasons for having ECT

- 60% understood the reasons for having the treatment

> *"It did seem to break through the depression at the time"*

- 40% did not understand reasons for having the treatment

> *"Didn't really help at all"*

Benefits Experienced

- When asked if short-term benefits were experienced,
  - 46.2% said they didn't know,
  - 30.8% said No,
  - While only 23% said that short-term benefits had been experienced.

"It lifts depression"
"I wish they had left me alone. I don't know about benefits"
"No good, Bad in every way"
"Possibly, as I was also taking medication it was hard to say."

- When asked if long-term benefits were experienced,
  - 42.9% said no,
  - While 35.7% said that they didn't know, and
  - Only 21.4% said that they had experienced long term benefits

"It helps recovery, it got rid of delusions"
"No. Still depressed at times afterwards. Still had to take medication"

Side-effects Experienced

- When asked if short-term side-effects were experienced,
  - 57% said these had been experienced,
  - While 28.6% said that they had not been experienced, and
  - Just 14.3% were unsure

"Loads"
"Headaches and loss of memory"
"Not as sharp as usual, memory loss"
"Feel very groggy afterwards"
"I don't recall any."
"Memory, mixed up,"
"I lost sensory perceptions"

- When asked if long-term side-effects were experienced,
  - 50% said these had not been experienced,
  - While 35.7% said that they had been experienced, and
  - Just 14.3% were unsure.

"Could have effected learning ability"
"Less than 100% yourself, lose capacity in life"
"Long-term memory loss."

"I always feel that long-term it damaged my memory. I read somewhere that this notion has been disproved. But that's what I feel. I can only hope the technique is a bit more sophisticated than before."

Feelings about ECT

People were asked about their feelings about ECT and the following is a sample of what was said. The majority of comments reflect fear and even coercion.

"Terrified"
"Felt terrified"
"I felt I had no choice"
"Terrified"
"Very scary, regrets"
"Not great"
"Horrified"
"Very scary. I regret it now."
"OK"

Additional Comments

When asked if they had additional comments on ECT the following , mostly negative, were given

"There must be an alternative"
"It should be banned, I didn't even know my own husband, he was a complete stranger to me for an hour or two"
"I feel ECT was helpful at the time"
"Very hard, very frightening"
"I don't want to have it again"
"Don't approve of it".
"I was asked for a year, I kept saying no, no, no"
"I liked it"
"I never discussed ECT after the first time. If ------- said it, I would have done it."
"Should have been explained more. I wouldn't have had it"
"There is no point in it unless there is no other solution"

Discussion

Given that, in ECT an electric current is passed through the brain, which results in epileptic-type seizures or fits, it is no wonder that there is a lot of anxiety and fear surrounding this treatment. It is prescribed in order to lift depression and to interrupt thought patterns. Although there were 3 audits carried out for the Royal College of Psychiatry in Britian, in the 1990's, each has shown ECT works in an unpredictable way, with random efficiency, and random damage. These audits admitted that doctors do not know how it works, or nor will they agree on how best to administer this treatment. Indeed the dose given being decided "by habit, rather than by rational decree."

Nearly half the people who had ECT were unclear about whether there were any benefits from it, while only about 20% said there were benefits. In the literature there are clearly documented unwanted side effects, which include; Memory loss, Headaches, Loss of concentration, Brain damage, and Brain lesions. Our respondents also reported experiencing these, and the reported side effects far outweighed the benefits (57% short-term side-effects, 35.7% long term side-effects). There is a wide diversity of opinion among our sample about the usefulness or benefits of this treatment, some would have it again and say it helped, and others were angry about it because of the side effects.

By nature of the fear and uncertainty that surrounds this treatment, the issue of consent is obscured; it is almost impossible to be sure that this is "informed consent". There should be a lot more information given to the user, and his/her family, on the possible benefits, and in particular, on the potential side-effects of this treatment, in order that the user is fully informed, and in a position to make an "informed choice". A peer advocate should be employed in order to facilitate the process of decision making around whether to have, or not have, this treatment.

Clearly this is a controversial subject for users, and even among the medical profession, given the wide discrepancy in prescription rates among doctors. The majority of reported feelings about ECT are quite disturbing, and range from outright terror, helplessness and apathy, to coercion. Therefore, it is imperative that the medical profession takes on board users' fears and concerns about ECT, and acknowledges and addresses these. Ongoing research, including evaluation by users, should be carried out in order to provide some justification for its use.

Recommendations

1. Considering the fear this treatment arouses, we would strongly suggest the mental health service explore the justification for using this controversial treatment, by carrying out further research into it's benefits.

2. If prescribed, the benefits, and particularly the side effects, should be adequately explained to the user, and his/her family.

3. A concerted effort must be made to give the user an "informed choice" by providing adequate information.

4. A peer advocate should be appointed in order to facilitate the process of obtaining "informed consent" from users prescribed this treatment.

5. A specific support and information service like the "Clozaril"clinic should be made available to people prescribed ECT.

Counselling / Talking Therapies

Introduction

In the absence of a specific counselling service within the mental health services it was difficult to define what constituted counselling, and identify which professionals offered this service. When designing this section it was decided to include talking therapies in the title to get a sense of service users perceptions and experiences of counselling/talking therapy.

Main Findings

Source and experience of Counselling/Talking therapy

- The main source of counselling/talking therapy was with
    - A mental health service psychologist 36.4% and
    - Group therapy 27.3%.
    - 12.1% attended a private source,
    - 3% attended a M.H.S. social worker and voluntary groups while
    - 18.2% attended others (nurse, occupational therapist, psychiatrist.)

- 70.6% had received some form of counselling while 29.4% had not.

'This should be offered within the unit.'
'Should be offered to everyone. Hard to get referred to a psychologist.'

Value of Counselling/ Talking Therapy

- 94% of respondents believed counselling/talking therapy was important**.**

'It should be used more often on a constant basis.'
'I think its very beneficial if its group therapy.'
'I am looking for it now, who, where to go to?'

- 'Of those who had not received counselling 93% believed it would have helped them.

'I feel I should have been referred to a counsellor or psychologist but wasn't.'
'I was never informed about counselling, and found out about it by myself . I find it good and think there should be more of it.'
'Could have used counselling in a crisis.'

⊄# The majority 83.3% of those who had experienced counselling found it beneficial while 13.9% did not and 2% did not know.

' I feel it is essential for me.'
' It did me good to talk about problems.'
Didn't find it effective.'
' I was too ill to appreciate it when given.'

Additional comments

⊄# The majority of additional comments were positive (31) reflecting a belief that counselling had helped, could have helped and should be more readily available through the mental health service.

'It's not as available as it should be and medication is relied on too much.'
'I felt talking therapy was given second or third class status to medication. I was never referred to a psychologist and feel I should have been.'
'Felt it would have helped and maybe would not have needed as much medication.'
' I was 14 years looking for counselling. I can't afford to pay and was only offered three sessions with the social worker. I am very angry and upset about this.'
"It's important to be offered it. I'm not a great one for talking, but you can get things off your chest."

⊄# There were 4 negative comments

"I was too ill to appreciate it when given."
It didn't appeal to me very mechanical.'

Discussion

The findings in this section are resoundingly positive about the role of counselling /talking therapy in mental health. The majority of respondents believe counselling /talking therapy is important (94%), was of benefit to them (83.3%), or could have helped them if it had been provided (93%).

These figures speak for themselves, service users believe in and want access to counselling/talking therapy. As previously identified in the section on medication, counselling/talking therapy is a preferred treatment choice for service users, other than or in conjunction with medication.

Despite the overwhelming interest in and demand for counselling/talking therapy, to date, it seems to have been provided, in an informal ad hoc fashion, by a variety of staff. This raises concerns about the quality of counselling /talking therapy currently available and the possibility of adhering to the professional standards set by the The Irish Association for Counselling and Therapy.

The I.A.C.T.I. believe that self-determination is an integral part of the counselling/therapy process. Self determination is undermined by the existing mental health referral system, where some one else decides who would or would not benefit from counselling/therapy. The qualitative comments in this section highlight users dissatisfaction with this system, as service users who felt they would benefit from counselling were not offered it while others may not have wanted to be referred.

The I.A.C.T.I. also state, "only when both parties explicitly agree to enter into a counselling relationship and a contract is agreed between the counsellor /therapist and client does it become counselling/therapy". As service users reported feeling pressured to attend groups in the acute unit and day hospital, and 27.3% of respondents cited group therapy as their experience of counselling/therapy, it is unlikely that contracting for counselling was standard practice in these groups.

Interestingly, the recent The Health Strategy 2000 (pg146) echo's our findings, stating that "concerns about using only the traditional 'medical' model of care for mental illness rather than considering alternative therapies such as psychotherapy or psychological treatments" need to be addressed.

If Mental Health Service providers are genuinely committed to implementing the recommendations of the health strategy and listening to service users, then it is incumbent upon them to provide an adequate professional counselling service, as a matter of urgency.

Recommendations

1. The Mental Health Services should contract or employ professionally trained counsellors/therapists as a matter of urgency.

2. Information clearly explaining the counselling/therapy process, and how to access it within the mental health services, should be available to all service users.

3. A system of self-referral should be put in place ensuring that every service user has an equal right and opportunity to access counselling / talking therapy services.

4. The impact/ effectiveness of counselling /talking therapy should be evaluated on a regular basis. These evaluations should be recorded and used to establish best practices and inform future developments.

Activities in The Unit

INTRODUCTION

Over two thirds (76%) of the participants attended activities while an in-patient in the acute unit. The activities department provides a variety of groups from Monday to Friday, which forms an integral part of in- patient treatment. This section has been designed to explore service users experience of these activities, and assess the appropriateness and usefulness of these activities in addressing the needs of inpatients.

MAIN FINDINGS

⌀ While 35.9% of respondents expressed a desire to attend activities, almost two in three, 61.5%, reported that they were "pressured" into attending. (An insignificant number were not offered activities at some stage of their stay.)

> *"Felt I was forced into them and just wanted to relax. No choice."*

Involvement in Planning Activities Programme

⌀ The majority of respondents, 84.2% reported no involvement in the planning of their own activities programme. 15.8% were involved in planning their programme.

⌀ Most respondents, 78.9% believed that it would have been helpful to be involved in the planning of their activity programme, while only 10.5% felt that this would not be useful.

Usefulness of activities:

⌀ Two-thirds 66.7% viewed activities as helpful in their recovery but almost one in three 30.8% did not.

⌀ Respondents had attended a broad range of activities but there was little consensus about which or why activities had been useful/enjoyable or not. This is reflected in the qualitative responses where most groups were mentioned but the following groups were mentioned most often.

> **Art:** 7 respondents found art most useful while 4 found it least useful.
> *"Painting, art: found more therapeutic than other activities. "*
> *"Painting didn't suit me."*

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Group Therapy: 7 respondents found group therapy most useful while 5 found it least useful.
"Group therapy: Because I could talk to other patients who had depression as well."
"Group therapy – too stressful."

Gardening: 2 found gardening most useful while 9 found it least useful.
"Gardening: It was healthy to get out of the hospital environment."
"Gardening, not interested."

Choice, and suggestions

⧸# 71.8% would have liked more choice in the groups on offer in activities.

"People should be able to choose more what to do – e.g., bingo."

⧸# Participants suggested a number of activities they would like to see included in activities. The activities mentioned most often were physical activity, music therapy and outings from the unit.

"It would be nice to get out of the place, go for a walk, instead of walking up and down the corridor."
" Music therapy: They did a study on music and depression, and they found it helped in 34% of cases."
"Fitness, aerobics something physical."

⧸# Despite the obvious interest in physical activity 77.5% of respondents stated that they did not have any physical exercise while in the Unit.

" A few gym machines should be put in."
"Healthy body and healthy mind go together."
"No release mechanism in place for strong feelings."
"Get more fit, less helpless."

Activities Extended beyond Office Hours

⧸# 71.1% of users would like to see activities provision extended beyond the Mon.-Fri. 9-5 confines as evenings and weekends can be difficult for inpatients while 28.9% felt they needed time to themselves and did not want activities extended.

"Smoking cigarettes and drinking tea all day."
"Sometimes, if you don't have visitors, the weekends are hardest and the evenings longest."

"No because you need time for visitors ... and weekends for home visits."
No, people need their own time."

Boredom in the Unit

∉ 82.5% of users reported that they experienced boredom during their stay in the Unit.

∉ The large majority **(**87.2%) believed that day trips out of the unit were a "good idea" and the following were some of the outings suggested.

"Going out for a walk, out of the hospital".
"Anywhere that would give you something to talk about, get away from the monotony."
"Walking to the shop, the canal, fresh air, break the monotony, the garden is enclosed too. "

Additional comments

š˙ To conclude this section participants were asked if they had anything to add to the subject of activities. The majority of responses were negative with a general consensus that there is need for improvement.

" They don't know what to do with us. "
"Very old fashioned - has not changed for years- very boring"
"Activities could be better organized a lot of time is wasted."

DISCUSSION

From the large volume of qualitative responses in this section (only a proportion of which were included in the main findings) it would appear that respondents were interested and invested in this subject. Although the comments varied greatly, many reflected strong feelings, and evidence, that despite being acutely ill, respondents had a clear sense of what they needed and wanted from activities.

Unfortunately, most respondents were not provided with the opportunity to express these needs as they were not consulted or involved in planning their activity programme. It would seem that, informing service users about the activities on offer, and allowing them to decide for themselves which activities might be meaningful or relevant to them, is not standard practice to date.

This lack of collaboration may be contributing to the perception service users reported of being pressured to attend activities. Perhaps staff feel justified, in pressuring service users to attend activities, when they do not want to, or are incapable of making such decisions, because it is judged to be in the best interests of their recovery. But care must be taken that this practice does not reinforce a sense of helplessness and undermine the possible therapeutic value of activities, because users feel mandated to attend them. Whatever the rationale for not involving all service users, it is important that this is addressed, as so many respondents believed that this involvement in planning their programmes would have been helpful to them.

Although two thirds of the respondents felt activities helped in their recovery it is worrying to note that one third did not find them helpful. Evaluating the perceived usefulness of activities is complicated, as respondents who felt pressured to attend an activity, may have been less receptive to the possible therapeutic value of that activity. It is also difficult to evaluate the usefulness of individual activities. For each respondent who found an activity valuable or enjoyable, another respondent did not. What we can conclude is that respondents had a wealth of knowledge about themselves, and how and why activities did or did not benefit them. This knowledge, if requested could have been used to provide each service user with the most relevant and meaningful programme possible.

Unlike the above findings, there was consensus amongst respondents about how activities could be   improved. Greater choice and extending activities to evenings and weekends were mentioned repeatedly, which could possibly reduce the high levels of boredom respondents experienced.
There were specific ideas for increasing the choice in activities with something physical and music therapy suggested most often. This may reflect a general desire, to release the stress of being unwell or being in hospital, in a physical or creative way.

In conclusion, it is apparent that activities are an important part of treatment in the in-patient unit, but to date it would seem that users have had to fit in with activities rather than activities fitting the needs of individual users. In essence, improving the experience of activities for in- patients may have less to do with, what is currently on offer and more to do with how this is being offered.

If we accept that a key component in recovery is a user's active participation in treatment, it is essential that this is actively facilitated and encouraged at every stage of treatment. By not informing and allowing in -patients to decide on their own activity programme we are discouraging active participation and undermining the individual's responsibility for their own recovery.

RECOMMENDATIONS

1. Every in-patient should be

    a. Informed about the purpose and structure of each activity.
    b. Involved in planning their own activity programme.
    c. Allowed to decide for themselves if they wish to attend activities.

2. All activities should be routinely evaluated to ensure they are meeting the needs of individual patients.

3. All evaluations should be recorded and used to establish best practices and inform future developments.

4. Where possible suggestions from patients (e.g. music therapy and exercise) should be incorporated into the programme and assessed at a later date.

5. Consideration should be given to extending the activities programme to evenings and weekends and including more outings from the unit.

Crisis while in the Unit

Introduction

This section addresses experiences of crisis for inpatients in the unit after hours i.e. when day staff had gone. This was included because some of the research team had experiences of major problems with crisis management in the unit after hours. This section explores how the services dealt with these events.

Main Findings

41% of the sample experienced an after hours crisis while in the unit

People were asked if the crisis was handled to their satisfaction. The responses obtained were fairly evenly divided into reports of satisfaction and dissatisfaction

"The nurse was there, hands on, talking, calming, reassuring. They did a lot of work prior to the doctor coming".
"No I had a phobia about meals, so staff wanted to give me an injection and I wanted to do it myself, there was a big row and I was held down and given the injection"
"Once when I was suicidal I saw a doctor after half an hour, other times you could be waiting two to three hours"
"It was, I was adamant in wanting to go home, I was calmed by nurses"

Respondents were invited to offer their own recommendations for improving the response to crisis in the unit. The following suggestions were made:

"If they explained what was happening e.g. "the doctor is held up" Instead of saying "yeah we are getting the doctor" and disappearing"
"The last time I was in they had three specials and only two nurses. They didn't have the nurses to cope"
"There should be easier access to the doctor and not have to wait to long for him"
"They should be dealt with more speedily. The nurses are left to reassure you. They should have more authority"
"You have to wait too long for a doctor"
"The doctors and nurses should take a crisis more seriously"

Discussion

Half the comments on after-hours crisis were positive. This indicates the potential to build a better service. Many participants felt nursing staff were overworked, particularly during after-hours. They therefore felt responses to crises at these times were not as adequately dealt with.

The most effective action embarked upon by the professionals might simply be to reassure the user going through the crisis by providing a listening ear. More hands on caring and more understanding were both given as examples of useful skills. Another major concern of participants was the time taken by duty doctor to respond to a crisis. Training in crisis management for nursing staff may reduce the demand for intervention by medical staff.

Recommendations

1. Given that the nursing staff have been shown to play such a big role in reassuring patients in crisis, a review of the current policy of reducing staff levels at the weekends and evenings is urgently needed

2. Because of the frequent delays for users in crises being seen by a duty doctor after hours while in the hospital we recommend that a duty doctor be assigned full-time to the mental health unit since the system of sharing a doctor between the mental health unit and casualty does work effectively.

3. Since so many patients found reassurance from nurses a great help, nurses should be given the time to spend with patients especially those in crisis

4. Ongoing training in crisis management must be a priority for service development.

5. A more holistic approach to crisis response should be explored rather than sole reliance on medication.

Preparation for Discharge/Aftercare

Introduction

Facing the real world after a period in hospital can be a daunting prospect. Some service users may have to deal with changed work, social, family roles together with fear of relapse and the stigma of being in a mental health institution. Thus preparation for discharge is extremely important in assisting the service users transition from hospital to home. This section has been design to explore users' experiences of discharge and preparation for discharge from the psychiatric unit.

Main Findings

Importance of day/weekend leave: -
⊄# 90% of respondents replied that day/weekend leave was important to their recovery.
> *"A lot of people benefited from day leave. It's very claustrophobic in the unit. It's an institution"*

Importance of user involvement in planning leave

⊄# 80% of respondents replied that involvement in their planning for their discharge was important to them.
> *"Should prepare you for discharge slowly, bring you out to get you used to the outside again."*
> *" When admitted the second time I was ready to go home bout on the first occasion I was forced to go home"*

User involvement in planning discharge

⊄# 52% of the survey reported that they had not been involved in reaching the decision to discharge.
> *"(Say)-that if you were given leave for a day, by the time you got things sorted – got meds-etc-day gone"*
> *" I know if I had stayed any longer I would have got worse. I kind of lied and pretended I was better than I was"*

Beneficial for those who were involved

⊄# 94% of those participants who were involved in planning their discharge felt that this process was of benefit:
> *"I wanted to have as little as possible to deal with the unit and the M.H.S."*

⊄#

Adequate notice for those who were involved

24% of participants believed that the notice provided for them, in terms of date for their discharge, was inadequate.

"They were saying I should go, I didn't feel ready. Were they trying to get rid of me? I went home and had to come in again"

Self-discharge

25% of respondents stated that they had discharged themselves from the Psychiatric Unit.

"I discharged myself after 18 hours. I didn't like it there at all. I felt safer at home"

Fearful of discharge

65% of the sample reported that they were fearful of discharge.

Main areas of concern over discharge:-

# Worried about relapse	…………………	76.3%
# Coping with everyday tasks	…………………	73.7%
# Isolation	…………………	68.4%
# Rehabilitation	…………………	63.2%
# Crisis management	…………………	50.0%
# Community attitudes	…………………	47.4%
# Employment	…………………	39.5%
# Financial worries	…………………	36.8%
# Living arrangements	…………………	34.2%
# Institutionalised	…………………	28.9%
# Other	…………………	5.3%
# None	…………………	2.6%

Professional contact over concerns

51% of respondents stated that they did not have any contact or counselling with medical and health care professionals to discuss their worries about discharge.

No because they were more determined for me to be discharged than I was.
I did not have adequate contact with any relevant professional.
Didn't bother

Contact Reassuring

≠# 75% of participants who had with professionals found it reassuring:
> *Yes, follow up care good. Appointments and community nurses good.*
> *Yes, I saw the consultant once a month, and could also see him in-between if necessary.*
> *I spoke to a nurse*

Services Perceived as Useful

≠# Support Groups ……………………….. 95.0%
≠# Information packs ……………………….. 80.0%
≠# Planning for discharge group……………… 75.0%
≠# Mediator/advocate ……………… 67.5%

Levels of satisfaction with post-discharge care

≠# 58% of the survey reported that they were satisfied with their follow up services.
≠# 42% of participants reported they were not satisfied

> *Never got an appointment to come back*
> *No Community Nurse…no Social Worker…I don't think they care.*
> *There was no follow-up contact from any professional except the brief three monthly chat with my consultant.*
> *Not the doctor for the following six months of care.*
> *No back-up from the unit, you're forgotten about once you're discharged.'*
> *Had community nurse-was satisfied.*
> *Referred to day hospital and found that good.*
> *Found the day hospital very good.*

Discussion

In the recently published Health Strategy the national goal no. 3 is identified as 'responsiveness and appropriate care delivery'. The first objective associated with this goal is that the user is at the centre in planning care delivery. This means developing responsive health care systems, enabling service providers to listen to and accommodate individual service users wishes. This objective is extremely pertinent in the area of planning for discharge.

As the results show in this section user discharge from the unit can be a worrying experience. We ask the question, why were 49% of users not involved in the preparation for their discharge? Yet 94% of our participants who were involved stated it was beneficial. The Inspector of Mental Hospital's Report (2001) states that the "revolving door phenomenon" has greatly increased since the 1970's. We also ask the question if users are placed in a passive role with regard to discharge does this not greatly increase their dependency on the services rather than facilitating the recovery process?

This survey indicates a self-discharge rate of 25%. This is significantly higher than the rate for the general healthcare services and warrants investigation.

A majority of users were fearful of discharge. Why is this? As the survey indicates, there is a plethora of worrying reasons. To address these, which are both medical and social, a new attitude to user care, based upon inclusiveness and collaboration must be introduced.

Although administrative and medical discharge guidelines do exist, they appear to be inadequate from a user's perspective. Some of the perceived useful supports are in place or being explored. A large percentage of respondents (67.5%) are in favour of a mediator/advocate. This seems to suggest that this particular pre-discharge support should be provided.

Despite the fact that a slight majority (57.9%) were satisfied with follow-up care, the current system may still be described as unsatisfactory, out of touch with user needs and in urgent need of review.

Recommendations:

1. A mediator/ advocate should be appointed to help prepare users for discharge.

2. User's involvement in planning for their discharge should be given a priority.

3. Adequate notice for discharge should be a very basic right

4. Further research into comparative rates of self-discharge from general acute settings and similar mental health acute settings.

CONTACT WITH PROFESSIONALS

Introduction

It is generally accepted that the human face of medicine that is the relationships with professionals is as important as any medical intervention. In Mental Health Services communication is essential for appropriate diagnosis and treatment planning.
As diagnosis and subsequent treatment are primarily determined by doctors contact with doctors is explored in more detail than the other professionals.

Main Findings

Adequacy of Contact with Doctors

⊄# 63% of users found the number of doctor visits adequate.
32.6% of users found the number of doctor visits adequate.

⊄# 50% of users said doctor visits lasted 5-10 mins.
⊄# 49% saw the doctor for 12-20 mins.

Issues Discussed with Doctors

⊄# Main issues discussed were: 34% mentioned Mood, 26% mentioned Medication, 18% mentioned Sleep, 12% mentioned Appetite and 8 % Illness.

> *"Felt that I was asked the same questions every time, how are you feeling, eating, sleeping, suicidal?*
> *"Feel the standard set of questions are inadequate"*
> *"Am I taking my medication, how are my thoughts, do I realize that my problems are due to psychiatric illness, am I sensible enough to come in if something is wrong?"*

⊄# When asked about issues the users would like to have discussed but didn't (23 out of 50 people) respond with issues that they would have liked to discuss.
The main issues fall under the follow areas:

(a) Medication/Diagnosis/Side effects of Medication.

> *"I would like to know how long I have to stay on Lithium, the likely outcome of manic depression, that type of stuff, they don't have the time"*
> *" Wanted to discuss Medication more, felt doctor didn't want to discuss it"*

60

"Symptoms, I would like to discuss those more in depth"
"Nothing explained, side effects etc."
"Yes, long term effects of pills, never been told"

(b) Feelings/ Personal problems

"Would have liked to discuss my own problems but doctor never seems to listen"
"Yes, how to feel happier, friendships"
"How I am really feeling, for example, paranoia, not superficial stuff"

⊄# 51% found it easy to discuss issues relating to them with their doctor.
⊄# 42.9% did not find this easy.

"I have problems communicating, which only now after 5 years they are addressing"
" I find my doctor hard to approach, very business-like, if I had a more talkative consultant I might talk more"
"I asked nurses to go with me to back me up but they couldn't. I was so afraid of him"

Continuity of Doctors

⊄# 73.8% said that they did not see the same doctor in the past six months. 26.2% said they did.

"I'd rather see the same doctor, someone that knows you, understands you, you've to answer the same questions over and over again."

⊄# 53.8% clamed that the new doctor was unaware of their case history.
⊄# 34.6% clamed that the new doctor was aware of their case history.

"Doctors got me mixed up with another patient once"
"They read my file in front of me"

⊄# When users were asked about the effect of the new doctor being unaware of case history.

The main issues were:

(a) (8people) a large number of people reported strong negative feelings e.g. frustration, anger, feeling upset, and confusion.

"Frustrating, had to explain whole thing again, had not read up on notes and did not have a clue"
*"Upset and angry"*

"They had to find and read through the chart, or get me to explain it, it was very (raw) for me"
"It upset and confused me"

(b) A substantial number of people (9) reported that this undermined their confidence in the system, it was unprofessional.

"You lose confidence in the system, it should be somebody who knows you"
" It bothers me, the whole system bothers me, comparing it with England and Holland the facilities are terrible"
" I thought that it was unprofessional"

⊄# The Professionals - (Doctors, Nurses, Community Psychiatric Nurses, Occupational Therapists, Social Workers and Psychologists) were rated from very poor to very good under the following headings - Active Listener, Encouraging, Respectful, Effective, Approachable and Understanding.

Please Note: For the purposes of analysis, responses that fall under the ratings of adequate, good and very good are grouped under the affirmative, while poor and very poor are grouped under the negative.

Figure 1 Ratings of Doctors
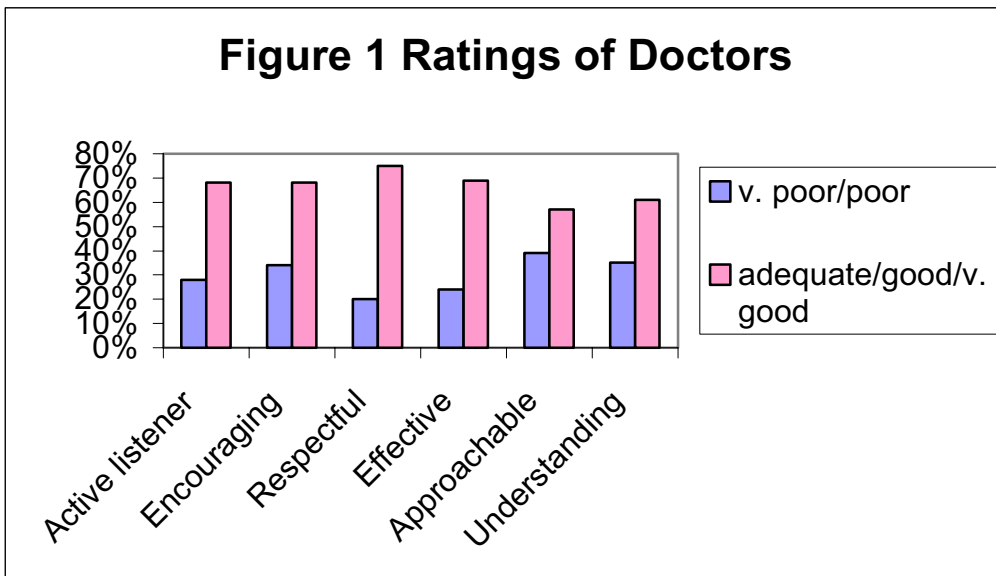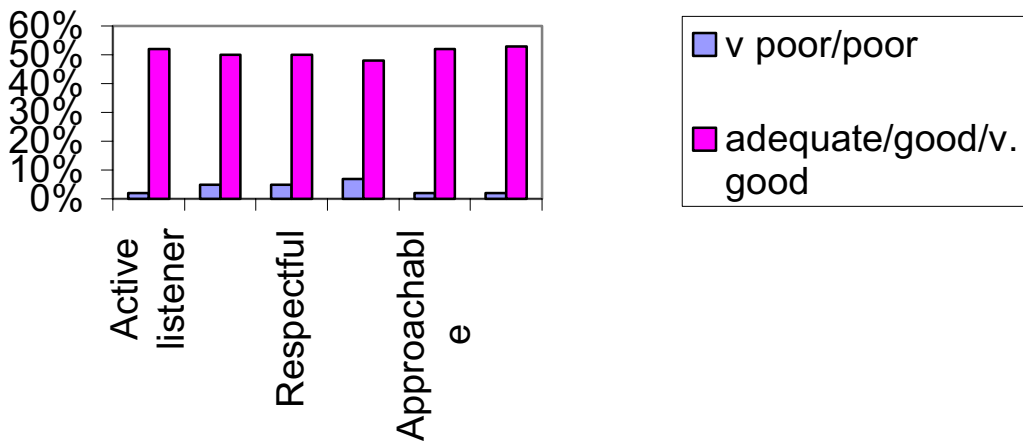
Figure 2 Ratings of Nurses
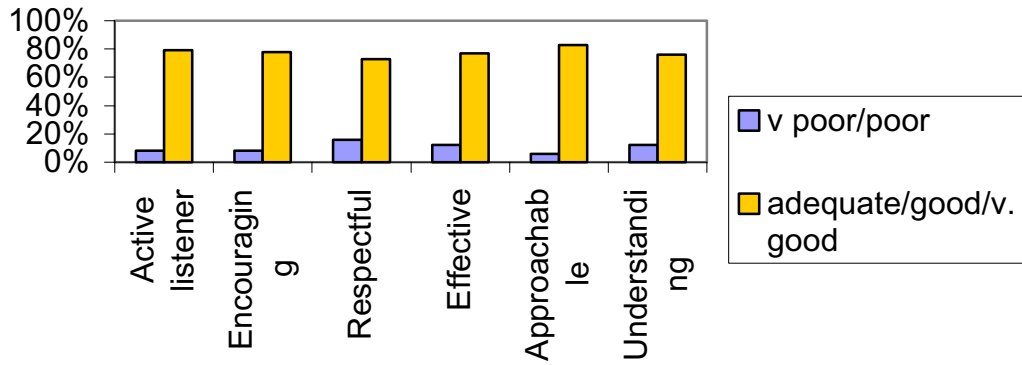
Figure 4 Ratings of CPNs

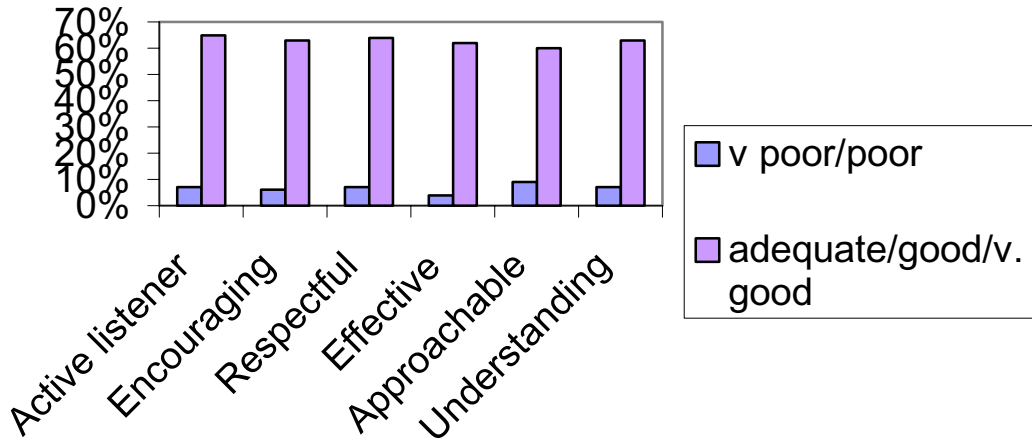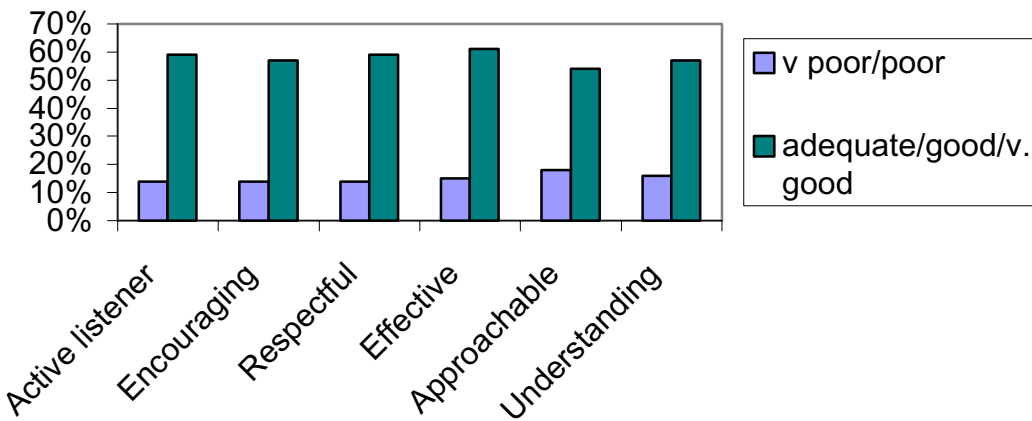Figure 4 Ratings of OTs

Figure 5 Ratings of Social Workers

Figure 6 Ratings of Psychologists
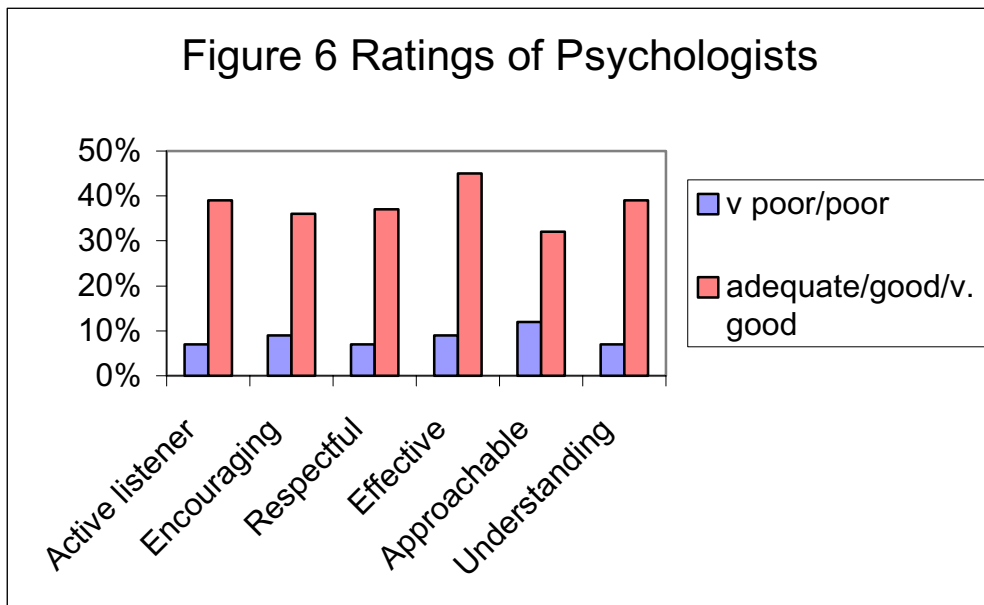
- The approachability of doctors and psychiatrists stands out as their weakest attribute.
- The approachability of Nurses was their strongest attribute.
- O.T.'s, C.P.N.'s and Social Workers are strong in all attributes.

Additional Comments

- People were asked at the end of this section if they had anything further to add.
  Overall comments indicated a desire on the part of service users to have increased time and access to all mental health professionals.

"If the professional would talk more about anything and not to feel that you are prejudged"
"Social Workers are hard to access"
"I want to get an appointment with a Psychologist. I was promised over a year ago but it has not happened"
"Sometimes treated like a child, rated lower that professional because you have an illness"
"I think that the nurses are a little abrupt a lot of the time, it's hard if you don't get on with them."
"I think that they do not listen enough and do not spends enough time with patients"

Discussion

If contact with any professional is to facilitate open honest discussion an environment of understanding and trust needs to be created. For a service user to develop trust and belief that the system is working in their best interest they need to be familiar with and trust the decision maker in charge of their treatment.

It is evident from these findings that the existing system is not conducive to forming such relationships. Where doctors were concerned, respondents reported that they did not see the same doctor consistently (73.8%), doctors were not familiar with their file (53.8%) and consultations usually lasted 5-10 minutes . There appears to be no scope within the existing system for both professionals and service users to develop a therapeutic relationship.

In the absence of a therapeutic relationship communication is undermined. This was reflected in our findings in various ways. Nearly half of the sample found it difficult to speak to their doctor about issues that were important to them. They wanted to talk about personal feelings, problems and implications of their drug therapy. But the main issues that were discussed were the symptoms of their illness.

This indicates that the "Medical Model" is still clearly entrenched in the West Galway Mental Health Service. The medical model looks at illness, not the spectrum of human experience, which of course includes health. Typically the medical model looks at mental health problems on their own as if they exist without reference to everyday experience.

The feelings expressed by users of distress, anger, and frustration and their loss of confidence in the system clearly highlight the inadequacies of the medical model. There is a strong desire amongst service users to have access to a range of professionals, to talk more openly and honestly about their recovery needs, both within and outside the service.

If the service providers want to respond to the desires expressed by users then a more flexible open model like the Bio Psycho Social Model needs to be adopted. This model views the person's life experience of health or illness as being the result of a variety of complex factors which include environment, genetic predisposition, relationships, job and family. Thus recovery involves addressing not just the symptoms but also the whole experience of mental health difficulties.

Recommendations

Alternatives to the existing "Medical Model" should be explored and adapted to ensure service users have the following rights :

1. Receive respectful treatment
2. Refuse treatment or a particular intervention strategy
3. Ask questions at any time
4. Know a professionals availability and waiting period
5. Have full information about your professional's qualifications, including registration, training and experience.
6. Have full information about your professional's areas of specialization and limitations
7. Have full information about your professional's therapeutic orientation and any technique that is routinely used
8. Have full information about your diagnosis, if used
9. Consult as many professionals as you choose until you find one you are happy with
10. Experience a safe setting free from physical, sexual or emotional abuse
11. Agree to a written contract of treatment /care
12. Talk about your treatment with anyone you choose, including another professional
13. Choose your own lifestyle and have that choice respected by your professionals
14. Ask questions about your professional's values, background and attitudes that are relevant to therapy and to be given respectful answers
15. Request that your professionals evaluate the progress of therapy/treatment
16. Have full information about the limits of confidentiality
17. Have full information about the extent of written or taped records of your therapy/treatment and your right of access
18. Terminate therapy/treatment at any time
19. Disclose only that personal information that you choose
20. Require a written report on therapy/treatment
21. Have access to any written summaries about your therapy /treatment

(British Psychological Society, (2000). Recent Advances in Understanding in Mental Illness and Psychotic Experiences. Leicester. BPS.)

PRIVACY

Introduction

It is likely that privacy for users of the mental health services may be a more pressing demand than for those using the general health services, given the particular illness experience as well as negative societal attitudes, discrimination and stigma attaching to this group.

As such, it was agreed by the research team that a separate section should be devoted to the issue. It has been designed to allow the sample to catalogue their relevant experiences and express their opinions on the privacy afforded to them by the West Galway Mental health Services.

Main Findings

Respondents were asked if they found levels of privacy adequate, in both the inpatient and outpatient areas. They were also asked if they had requested more privacy and if their request was unsuccessful, for what reasons.

Adequacy of privacy

⊄# 50% found levels of privacy inadequate in the inpatient setting while a smaller number (35%) found privacy inadequate in the outpatient area.

This finding is illustrated by the following comments:

"Should be more in 1ˢᵗ few days, everyone knows everyone else's story."

"Feels it could be a lot better. Felt everybody knew everybody else's business."

"I feel there should be more privacy when talking about problems when in the Unit"

"Should be more privacy. Waiting area too open – waiting room should be in a room where you cannot be seen."

"There should be more room allocated for privacy, like a library for reading… the telly is on all day, morning and night. It is not conducive to your depression or if you need a bit of peace and quiet."

"There should be more privacy at outpatients."

"There is no privacy in the unit or as an outpatient."

*It must be noted that about half the respondents were satisfied with the levels of privacy.
This is illustrated as follows:*
"It wasn't an issue"

"I didn't expect a whole lot of privacy in the general ward. It was ok."

Requesting more privacy

- 87.5% of those who expressed dissatisfaction with privacy as an inpatient reported that they had not asked for more privacy.
- 91.7% of those who found privacy levels inadequate in the outpatient area did not request more privacy.

Of the small number who had asked for more privacy,

- 40% reported they did not receive it, no reasons were offered.

Some illustrative comments on this question:

"I did not have right to request privacy – felt I was cheeky if I did request it."

"It's a very, very busy place. They did their best. Not everybody can have a private room."

Discussion

Privacy, for all users of health care services is not just a core desire, but also a basic human right. This right is upheld in the Charter of Rights for Hospital Patients (1992), which states that the dignity of the individual is respected at all times. Half of those sampled (50%) found privacy adequate. However, it is to be hoped that service development aims at satisfying a much higher percentage of the population it serves, especially in basic rights such as privacy. These findings strongly suggest that there is much room for improvement.

Speculation as to why such large proportions of the sample did not request adequate privacy might include such explanations as – lack of assertiveness; fear; a desire to get out of hospital as quickly as possible; low expectations of having privacy needs met in hospital setting.

Recommendations

1. In line with **Objective 1**: *The patient is at the centre in planning care delivery* in National Goal No. 3, Responsiveness and Appropriate Care Delivery, *Health Strategy 2001*, we recommend that service users are asked during first contact or as soon as appropriate afterward, about their privacy needs and that these needs are given a high priority during subsequent planning and implementation of care.
2. Given the high percentage of those who found the privacy level lacking and did not seek an improvement, we suggest that service providers investigate perceived barriers to communication between service users and staff.

Chapter Three

Community Care

Crisis outside the Unit

Day Hospital

Day Centres

Training Centres

Crisis outside the Unit

Introduction

This section investigates critical experiences for outpatients and looks at the nature of responses from medical professionals to the crisis. The majority of the research team found that the only place to go in a crisis outside office hours was casualty.

Main Findings

A large majority (70.7%) reported that they that they experienced situations that required help outside the unit in the evenings or at weekends
84.8% reported that they sought help to deal with crisis
65.2% went to casualty for help
Only 4.3% went to their GP

The Casualty Experience

40.7% said casualty was not helpful in dealing with their crisis
84.6% of those who sought help from casualty said the time they spent waiting to be seen in casualty added to their distress
19.2% people left before being seen

People were asked how they found the experience of going to casualty most said it was very distressing:
"No help they couldn't do anything no bed"
"Daunting. A lot of people in small area"
"It just scares you. You're waiting around the pressure is building up inside you. You just wouldn't want to go there"

Nearly all the quotes we received used the words 'Frightening and Distressing'

Best Place to go in a Crisis

People were then asked where the best place to go in a crisis would be, they replied
"Straight to the unit"
"Unit"
"Directly to the unit"
"The unit" (Multiple responses)

Additional Comments:

"I don't think casualty is the best place to go"
"Should be someone in the unit at all times"
"I think going through casualty and the long wait is very distressing and staff are very ignorant"
"Something should be offered other than medication; sometimes you just want a reassuring talk with someone. Here you go to casualty, they get the psychiatrist to come and look at you and you feel your just going through the motions"
"I saw a mental health doctor who said "what's wrong with you this time" It was like an interrogation when I was already fragile"

Discussion

From the findings of this section it is clear that casualty remains the main point of contact for the majority (65.2%) of service users who experience a crisis outside the office hours. Most people were already distressed when they arrived in casualty and said they spent over an hour waiting to be seen, some a lot longer. The majority (84.6%) thought that casualty was not the best place to go in a crisis, and said that the experience added to their distress. Anecdotal evidence suggests that many peoples' first contact with the service is through casualty. If 19.2% of our sample left casualty without being seen, what percentage of the overall population leave without being seen?

The fundamental goal of crisis care should be to alleviate the distress of users in crisis. The present system of accessing crisis care through casualty does not achieve this goal. Only (4.3%) of service users in crisis went to their GP. Is this because the out of hours GP service is inaccessible? This suggests an alternative community based crisis response needs to be explored.

Recommendations

1. In order to make the service more accessible, we recommend, a doctor be assigned to both the unit and casualty at all times.

2. We recommend that after hours crisis should be handled within the unit in line with service users wishes in order to minimize distress.

3. A new model such as the Home-Based Treatment approach should be adopted.

Day Hospital

Introduction

Just under two thirds of the participants surveyed attended the day hospital. According to the document "Planning For the Future"(pg34) "the function of the day hospital is to provide intensive treatment equivalent to that available in a hospital in-patient setting for acutely ill people." In an effort to compare treatment in both the day hospital and in-patient unit it was decided to focus on the activities programme, as this provides much of the daily structure for treatment in both settings.

Main findings

Most and least useful activities

- A wide range of activities (17) was listed as being useful. Of these, art was mentioned most often (10), then crafts (3) and social skills and table tennis (2). The remaining activities were mentioned once and ranged from Assertiveness training to hot dinners.

> *"Art you didn't have to talk to anybody."*
> *"Art let your imagination run free."*
> *"Table tennis and hot dinner."*

- There were 8 activities listed as being the least useful. All of these activities, excluding the job club, were also mentioned in the most useful category. Gardening was mentioned most often (5 times) followed by art (4) as being the least useful.

> *"Job club, too stressful."*
> *"Gardening, I don't like it."*
> *"Art and crafts, no flair"*

Suggested changes

- 76% wanted more choice in activities, which was also mentioned most often (5) in response to the open question about changes respondents would like to see made to activities in the day hospital.

> *"Different things being done."*
> *"More choice, start computer classes, writers group."*

ø# Three respondents wanted the freedom to choose for themselves which activities to attend.

> *"You should not have to go to things you don't want to go to."*
> *"A course list would be helpful so you are aware of course that may be useful to you."*

ø# Three participants also experienced the programme as childish and patronizing.

> *"I thought the whole set up was a bit silly but I came along for the company. I was probably coping myself, with my friends. I felt like a child.*
> *"Home economics, how to look after yourself at home. I found this patronizing.".*

ø# 62% had experienced boredom.

Additional comments

Of the additional comments made at the end of this section 5 were positive referring primarily to staff.

> *"The staff were very professional."*
> *"They need more staff. Counseling very good. You were seen they were always in touch with you. Very involved. Helped a lot."*

5 were negative.

> *"I stayed for less than a day, I ran out of there so ludicrous I couldn't stick it."*
> *"I attended for just one or two days and didn't find it good".*

8 recommended other activities or changes.

> *"Lunch breaks should be shorter"*
> *"Set routine was repetitive."*

Discussion

The results for this section indicate that the day hospital is fulfilling its stated role, and providing a activity programme in the community similar to that offered to inpatients. We found that overall service users perceived staff positively and reported that a large number (17) of the activities on offer were considered to be useful. In relation to the perceived value of specific activities, the findings are very similar to those for the in-patient unit with little agreement about the individual merits of activities. It is worth noting that for some service users the hot meal, table tennis or pool were considered more useful than the structured activities.

Although more activities were viewed as useful than not useful, it would appear that service users attending the day hospital, did not have any more choice or involvement in planning their activities programme than in-patients did. Instead, respondents attended activities they *"disliked, did not enjoy, had no flair for or were too stressful,'* while others felt patronized and treated like a child. This could certainly contribute to the high levels of boredom reported (62%) which although lower than the in-patient unit (82.5%) is still unacceptably high. If we presume, that service users living in the community are less unwell than inpatients, and are attending the day hospital of their own volition, then the lack of collaboration in deciding their own activities programme seems hard to justify.

Overall, the picture is similar to that of the inpatient service. Both appear to be fixed systems, where all activities are presumed to have the same therapeutic value for all service users and the programme takes precedence over the participants individual interests and needs.

Allowing service users to decide their own activities programme would provide staff with invaluable information about the relevance to service users of specific activities. The expectation that service users, plan their own activities programme and manage their time would also encourage a sense of responsibility for their own recovery. Thus service users would attend for specific therapeutic groups rather than specific lengths of time reducing the likelihood of dependency on the service developing,

If we believe that the service user has any role to play in their own recovery then collaboration is essential in the planning and implementing of their own treatment programme. This type of collaboration would benefit both service users and providers, as the efficiency and effectiveness of any service, can only be truly evaluated in consultations with those it is supposed to help.

Recommendations

1. Each patient should be informed about the structure and purpose of each activity group and allowed to decide for himself or herself which groups to attend.

2. Patients should attend the day hospital for specific groups, rather than for specific times.

3. Patients should routinely evaluate the relevance and effectiveness of all activities.

4. Patient evaluations should be recorded and used to establish best practices and inform future developments

Day Centres

Introduction
Of the participants surveyed, only 25% attended the day centres. The role of the Day Centre, as defined by the Western Health Board, is to provide care for users who would not receive such care in a community care base. We included these centres in our survey to see if there was a difference between them, the Day Hospital and other community care available. Please note that many users went to both types of care centre while some users did not attend any.

Main Findings

Source of Referral, and Day Centre attended

- 81.8% of participants found their biggest source of information, or referral to these centres was from doctors. Other sources cited were nurses and social workers.
- 84.6% of participants attended Danesfield, while 15.4% attended Halla Padraig.
- 61.5% of participants felt they were pressurized into attending the day centre.

Rating of Staff by Respondents

- 91% of participants felt the staff were friendly. Participants were asked to rate staff. Most rated staff from adequate to very good.

Figure 1 Ratings of Staff Qualities
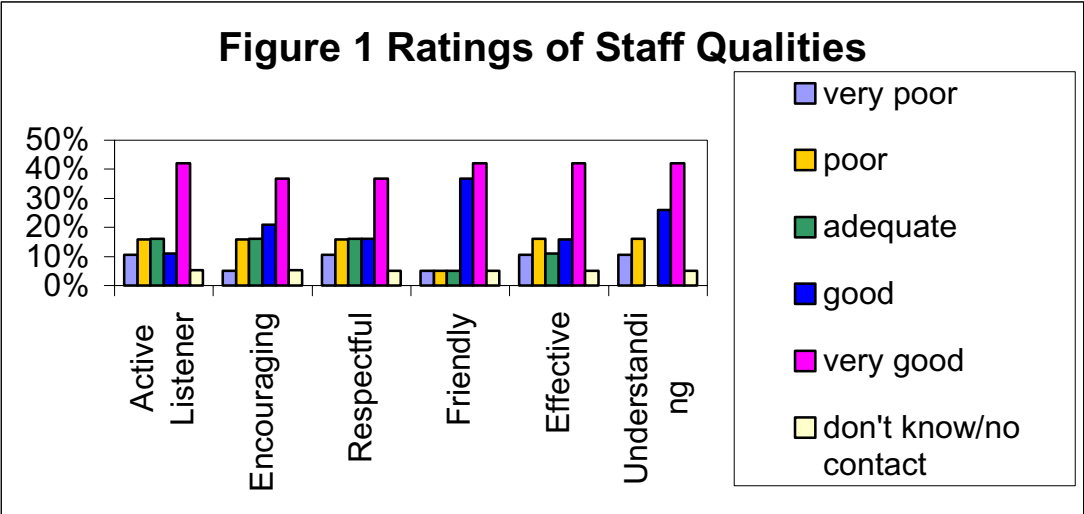
"I found talks with staff good. They actually listen to you."
"Better continuity of nurses."

Length of Attendance and Boredom

- 61.5% of participants attended the day centre for a shorter time than expected.
- 53.8% of participants did not find boredom a problem in the day centre, while 46.2% did.

"Found them all good.(activities)"
"Greater variety e.g. Creative writing, more arts and crafts and more chats e.g. Newspapers"
"Stupid activities not enough stimulation."
"Only childish games."

Discussion

Many of the activities were similar to those in the day hospital. Mentioned were gardening, woodwork, crosswords, quizzes, art, crafts, cards, creative writing, group therapy. There was no difference between the day hospital and day centres in the participants' attitudes towards these activities. The response on both, from the qualitative data, suggests that the participants liked the activities but there is need for improvement. Provided the user is involved in the planning and scheduling of his/her activities the more receptive the user will become.

Staff fared very favorably in both centres. This ends the notion of "us and them". Users no longer regard staff as custodians. Indeed there were many comments that recognized that staff were overworked.

Recommendations

1. Review the role and remit of day centres within the mental health services.

2. The agreed role of day centres should be based on the needs identified by service users .

3. The effectiveness of day centres should be evaluated by service users on a routine basis.

4. These evaluations should form the basis for best practice and future service developments.

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Training Centres

</div>

Introduction

Mental health difficulties can interrupt or interfere with educational and employment opportunities. When this happens, service users may need additional skills, guidance or support to access further education and employment. This chapter was designed to explore, how effective training centres were perceived to be, in assisting service users vocationally.

Main Findings

Use of Training Centres

- Over one in three respondents, 37%, had used Training Centres at the time of the survey whilst the majority, 63%, had not.

- The majority, 68.4%, had attended centres established to cater for people with disabilities, (Galway Training Centre, Parkmore , National Training and Development Institute.)

- 73.7% did not feel pressured to attend a training centre but over a quarter, 26.3%, reported that they had felt pressured to attend.

- When asked why they had attended a training centre, participants cited different reasons but the recurring theme was to structure or occupy time.

<div style="text-align: center;">

"No place else to go"
"Get something to occupy my mind"
"Because I was oversleeping and had to occupy my mind"
"To structure my day to get rehabilitated"
"Boredom"

</div>

Length of Time Attended, and whether Helpful, or not

- Almost half, 47.1%, attended for a shorter time than required, 35.3% attended for the expected length of time while 17.6% attended for longer than required.

- The majority, 70.6%, found that attending a training centre helped in their recovery, while 29.4% did not find the training centres helped them in their recovery.

- The training centres were perceived to be most helpful in, occupying time, 77.8%, learning to structure time, 72.2%, and peer contact, 72.2%

∉# They were perceived to be least helpful in learning about illness, 72.2%, developing new interests, 47.4%, and developing job seeking skills, 47.4%

Relevance of Training Centre

∉# Two thirds of respondents, 70.6%, did not look for work in the areas they had been trained in while 29.4% did.

∉# 70.6% did not receive a recognized qualification, while 29.4% received a recognized qualification at the end of their course.

∉# 61.1% experienced boredom as a problem during their training while 38.9% did not.

∉# 41.2% got work experience as part of their course, while 58.8% did not.

When asked if they had anything further to add to the subject of training centres there were some positive responses:

"Very impressive good skills, good to be working, good for self worth."
"I thought it was a very good course. It helped me get back on my feet."

And valuable recommendations:

"Provided good discipline and structure initially but not adequate to realistic vocational needs."
"Should get trainee involved more. More responsibility on trainee to perform and help (staff and centre)"

Discussion

The results from this section clearly indicate, that although training centres have generally helped participants in their recovery, they have not specifically helped service users vocationally.

It is interesting to note that only one third of the respondents attended a training centre and a quarter of those had felt pressured to attend. This means that a small proportion of this survey willingly participated in training. This finding is surprising, as few respondents were in full time employment, and the majority believed employment to be extremely important. However training does not appear to be perceived as a means of improving employment potential.

This is very much reflected in respondents' expectations of training .The main reasons for attending a training centre had little to do with enhancing labour market skills, but related much more to social factors such as occupying time. It would be valuable to explore why service users have such low expectations and how these expectations impact their training. These expectations may reflect how respondents feel about their own employment potential, what they believe training can offer them or what they have heard from other service users.
.
Either way, it is worrying to note that these expectations did not alter much as a result of training, as occupying and structuring time, along with peer contact, were perceived to be the most helpful aspects of the training while developing job seeking skills fell into the least helpful category. When we also consider, that less than half the trainees were offered work experience and the majority did not receive a recognized qualification it is not surprising that very few respondents looked for work related to their training. The apparent lack of emphasis on improving employment related skills could be presumed to contribute to so many experiencing boredom and the high drop out rate. As the majority of the participants attended centres established to cater for their needs this should be of particular concern to service providers interested in providing meaningful relevant training and enabling service users to achieve their full potential.

In conclusion it is very positive that participants were satisfied with the staff and facilities in the centres thus the basic ingredients for developing the service are already in place. The next step may involve looking at the role and remit of training centres, as currently this seems to be unclear and very similar to a day centre. As many service users seem to have low vocational expectations, clarification of what a training centre has to offer and how it differs from a day centre would enable service users to make a more informed decision.

Recommendations

1. Review the role and purpose of training centres and their effectiveness in assisting service users vocationally. Ideally this review should be carried out by service users.
2. Explore reasons for trainees low expectations, boredom and high drop-out rate.
3. Develop training programmes where skills directly relate to employment.
4. Develop links with recognized training agencies and employers to ensure the marketability of qualifications.
5. Provide work experience as an essential part of training.

Chapter Four

Aftercare

Employment

Well-being

Housing

Employment

Introduction

Employment is a key element of social inclusion. It builds confidence, generated a feeling of worthiness, structures the day, provides financial returns, and aids personal development. It prevents isolation, improves self-esteem. This section was included to explore the impact of mental health difficulties on employment issues.

Main Findings

Importance of Employment

⊄# 94% of participants surveyed stated that work was important to them.
"Employment is very important to your mental health"
"I'd love to be working even a part-time job. It'd be a reason to get up, have a wage packet to look forward to. It'd help in keeping sane."
"Work is very important to structure the day."

⊄# 40% of the participants surveyed stated they were long-term unemployed.
"People are afraid,. No trust"
"My medical history might go against me if I went for further jobs."

Effects of Mental Health on Employment

⊄# When asked did mental health effect your employment the following were the chief responses.

⊄# 94% of participants felt they were too sick to work at one time.
I had to leave jobs, usually on short notice. Therefore it doesn't look good on my CV.
Would be able if feeling well
I don't feel strong enough to work

⊄# 62% lost their job as a result of mental illness.

⊄# 67% had to change their type of employment as a result of mental illness
One employer and some employees knew there was something wrong with me and forced me out of work by treachery.

⊄# 37% had to drop out of college.

Help in Returning to College

⊄# 67% of participants stated that they did not receive any help in returning to work.

"Being shoe –horned back into the workplace. Eased back. A few hours gradually to build up your self-confidence"
"Rehab and O.T. Got tips and encouragement"
"Going down to (O.T.) She gives you a lot of encouragement. She's a nice woman."

⊄# 65% of participants were in paid employment before first experiencing mental health difficulties.
"At times necessary to settle for less because of illness"

⊄# 31% of the participants reported discrimination by employers and/or other workers. 57% did not report this.
"I feel there is a lot of discrimination against people with disabilities."
"Yes, I had a job before employers found out I was on Disability allowance."

Perceived Usefulness of Employment Supports
⊄# Mentor 65%
⊄# Information pack 84%
⊄# A list of contacts 88.2%
⊄# C.E. Schemes 72.2%
⊄# Training 70.%
⊄# Sheltered employment 79.4%

Discussion:

Employment is of a particular concern to mental health service users as we found in our survey people with mental health difficulties are ten times more likely to be unemployed. Although, the national figures are lower than 5% we found that 40% of participants were long term unemployed.

Yet 94% of our participants stated that employment was important to them for a plethora of reasons from something to get up for to providing structure and financial reward. 16% of the participants were in full time employment. Mental health difficulties had a negative impact on their employment prospects and potential. The findings catalogue a whole range of damaging consequences e.g. losing jobs, having to abandon higher education and being to sick to work.

A study (Mental Health Consumers Experience of Stigma, Schizophrenia Bulletin Vol.25 no. 1999) showed that more than a quarter, 27% of their sample were advised to lower

their employment expectation in life e.g. to accept jobs well below their level of education, intellect and training.

The employment difficulties experienced by services users are complex. We found that 67% surveyed had received no help returning to work and 31% surveyed reported feeling of being discriminated against by employers/co-workers.

Problems such as compiling a Curriculum Vitae, obtaining a sick certificate from the Mental health unit or being compelled to hide one's mental health history on application forms were reported as being major difficulties for many participants due to "fear of discovery"

Does this mean that service users are perceived to be too unwell? Does it mean further they are unsupported and discriminated against?

A more flexible innovative approach is required to identify and address underlying issues. It raises questions that promoting mental health should be an integral part of recovery with employment as a key concern.

In conclusion the findings in this section have raised far more questions than they have answered. We end this discussion by posing two questions.

1) Are service users unable to work due to mental health difficulties? Are they perceived to be too unwell? Are they unsupported and discriminated against?
2) Should treatment programmes address employment issues as an integral part of recovery?

Recommendations

1. Developing adequate and effective linkages between the whole spectrum of service providers for people with mental health difficulties on employment.

2. Explore the complex area of people with mental health difficulties and employment. Ranging from research, general public attitudes, and rehabilitation training to user self- empowerment.

3. Educate and involve existing/ potential employers of their role to play for people with mental health difficulties.

4. That the Western Health Board starts to employ service users and be pro-active in helping user to gain employment. Lead by example

5. That the Western Health Board employ peer advocates to assist service users

Well-being

Introduction

Wellbeing is regarded by the research team as one of the most important sections in the entire report. It acknowledges that service users are more than the sum of their problems and treatment and explores the myriad ways service users have learned to cope and recover from mental health difficulties.

Main Findings

Involvement with Organizations and Self-help Groups
- 23.5% reported involvement with "other voluntary organizations", then
- Sporting groups 19.6%,
- Religious organizations 13.7% and
- Social/political groups 7.8%.

Phrenz .	25.5%
Grow	19.6%
Samaritans	15.7%
AA	13.7%
Aware	13.7%
Others	17.7%

"Networking with other sufferers from support groups, developing hobbies such as art, and study such as history and art history, keeps me alert and interested in life."
"AA meetings, just talking to other addicts. I went out on 'Out and About'"

Positive, negative and complimentary coping strategies were put to the respondents. The following findings emerged from the sample:

Positive coping strategies:
1	Talking to friends	84.3%
2	Listening to music	78.4%
3	Hobbies	70.6%
4	Exercise	60.8%
5	Healthy diet	60.8%
6	Spirituality	45.1%
7	Gardening	39.2%
8	Dancing	27.5%

When we asked what coping strategies people had specifically found helpful 16 people mentioned sport and exercise,

"Exercise is a great thing. There is a buzz afterwards. Sometime you find you don't have the energy, but if you try it, you feel satisfaction. Like you have beaten it."
"Walking helps me keep fit and I thinks it does me good"

10 people mentioned talking to others, 10 found music helpful, and 7 found hobbies important. These responses strongly imply an impressive degree of commitment among the sample to using a variety of coping strategies to deal with mental illness, above and beyond the orthodox approach of medication alone.

"I lost three and a half stone in the last year. Taking more responsibility for my own life. Faith has carried me through a lot. I get huge support from family and friends"

Taking responsibility for one's own life and mental health is important, and empowering for the user, rather than being a passive recipient of services provided

Negative coping strategies:
1	Smoking	62.7%
2	Drinking	45.1%
3	Overeating	35.3%
4	Illegal drugs	13.7%

Alternative or Complimentary Therapies

There was a strong reporting of use of these as coping strategies – e.g.,
1	Meditation	31.4%,
2	Herbal remedies	20%
3	Aromatherapy	20.4%,
4	Massage	16%
5	Reflexology	14.6%
6	Homeopathy	14.3%,
7	Acupuncture	10%
8	Tai Chi	8.7%

⊄# 91.7% stated that they would increase their use of such therapies if they were eligible to receive these under the medical card system.

"There are so many alternative therapies that would be helpful but are out of reach financially"
"Acupuncture is supposed to be very good for my illness but I can't afford it"
"I would like the choice of alternative therapies"
"It would be nice if alternative therapies were available, in hospital or day hospital. Something with physical contact even the touch of a hand , incredible. Like massage, reflexology . Something with a feel good factor."
"There should be more information given on alternative health approaches. You are just offered medication now"

Mental Health Drop-in Centre

- 72.5% stated they would use a user-led mental health drop-in centre, if such were available,

"Yes because you would have somewhere to call into with people with the same problems as yourself."
"Especially run by others (who're mentally ill) because I know they understand better than going into the Unit and getting hospitalized."
"I'd make an effort to go ... meet new friends."
"No. I suffer from paranoia and would worry about confidentiality. I also believe mental health sufferers should be more integrated with healing people and not form a socially excluded ghetto."
"Love to talk about the way I'm feeling."
"Occupy evenings."
"They understand you better than the doctors."
"For the social activity. I was involved in a similar one in London. You are with your own, it can be very useful"
"Maintain contact with other people. It's important to have a network of support in times of difficulty"

Feelings about Illness

- 47.9% reported that they felt guilty about their condition;
- 92.2% reported that their mental health problems had a negative impact on their confidence and self-esteem;
- 84.3% reported that their illness made them feel isolated;
- 70.6% reported they felt socially excluded.

Comments around Stigma and Isolation

"Big stigma and isolation"
"I do feel stigmatized"
"There will always be a stigma. It affects me in that I didn't even have one visitor from work in 21 years. The whole environment doesn't understand mental illness"
"Stigma can hold you back."
"I've been called names."
"Stigma and isolation worries me"
"I have been more open than most, I've published poetry on my illness"
"Someone to talk to about isolation would help"
"There's an awful stigma, people try to treat you like a fool, treat you like a kid, like you've no savvy"
"There is a lot of stigma

Discussion

> *"The last of the human freedoms..to choose one's attitude in any
> given set of circumstances; to choose ones own way."*
>
> Viktor Frankl.

The findings in this section reveal a broad spectrum of groups, activities techniques and therapies participants are using to help them cope with their mental health difficulties. A large proportion of participants (72.5%) were involved with self-help groups and would use a drop in centre run by users (72.5%). These findings reflect the willingness of service users to take responsibility for their own recovery. The positive effect of involvement in self help groups were detailed in the report Knowing our own Minds 1996 which stated that "*there were substantial personal benefits: increased confidence, support, ideas for coping with specific problems, information advocacy and empowerment.*" (Pg 90)

There was strong reporting of the use of alternative /complementary therapies with the majority 91 % stating they would use these therapies more often if they were affordable. Research indicates that complimentary therapies offer significant benefits for people with mental health difficulties. Benefits include relaxation, the relief from tension or pressure and the experience of being treated like a 'whole person'. Knowing Our Own Minds 1996 pg 56. Unfortunately the cost involved precludes many service users from discovering if these therapies would benefit them thus rendering it very difficult to provide the evidence to persuade service providers that these therapies should be available through the mental health service.

It is clear from the findings that service users are committed to using positive coping strategies and taking responsibility for their own wellbeing.

Recommendations

1. Information about Self-help groups and relevant agencies should be made available to the users through the WHB.

2. A user-led mental health drop-in centre, such as Cruinniú, should be supported.

3. Holistic approach should be developed recognizing the importance of the physical, emotional, social and spiritual factors of mental health and recognizes the user as expert on his or her own experience.

4. Alternative and Complimentary Therapies should be made available to those on low incomes.

Housing

Introduction

Adequate housing and homelessness was an issue for the research team as most had known some mental health service user who was homeless when leaving the unit. The fear of never having a home of one's own was identified as a common experience of many users of the mental health services.

Main Findings

Reported Homelessness

⊄# 13.7% of the sample reported homelessness since using the mental health services.

> *"People should have a place to go on leaving the unit because homelessness is common among people with mental health problems."*

⊄# 27.5% of the sample reported they had lost their accommodation due to mental illness.

> *"I had a friend whose mother died while he was in hospital and because the house was rented, it was gone when he came out, he was homeless."*

⊄# 50% stated financial reasons for losing accommodation.

⊄# 45.7% said that the lack of adequate accommodation could exacerbate their illness, while 50% said it did not.

Current Accommodation

⊄# 90% said they had suitable accommodation now.
⊄# 31.4% had their own house
⊄# 31.4% were in private rented accommodation
⊄# 25.5% were living in the family home

Corporation Housing

⊄# Only 9.8% were living in corporation housing.

> *"There should be more council housing for single men in this town it's impossible to get a house. I've been on the waiting list for more than ten years and never got a letter through the door"*

⊄# While 26.7% said they were on the corporation waiting list.

"People with disabilities should be on top of the housing list."
"Should be more corporation houses."
"I think all mental health users should be entitled to a corporation house"

Discussion

Homelessness was defined for the purposes of our study as not having your own place, inadequate accommodation, and sleeping in a friend's place, as well as sleeping out or staying in a hostel. At the time of the survey none of our respondents were homeless, because in order for us to contact them for the survey they had to have an address. But 13.7% reported at least one episode of homelessness since they started using the services. This compares unfavourably with a national average of less than 1%, and clearly shows that people with mental health problems encounter the treat and reality of homelessness to a far greater extent than the general population.

An estimated 40% of the republics 5,000 homeless are mentally ill. The experts are divided on why they have fallen through the cracks of the social services system. Are they on the streets due to the closure of mental health hospitals or is it a lifestyle choice? (Kathryn Holmquist, Left out in the Cold, The Irish Times, February 8th 2002.) This raised the perennial question of which comes first, mental ill health resulting in homelessness, or homelessness causing mental health problems?

The finding that only 9.8% where living in Corporation housing is a worryingly small figure, compared to the large number who were in receipt of social welfare (68%). This means that a good deal of people with mental health problems are dependent on renting in the private sector, which because of poor tenancy laws, is very insecure. Also, those who are living in the family home can experience insecurities in relation to accommodation needs, when elderly parents die and the home is sold. The availability of Corporation housing was a big issue for most of our respondents, who felt that these should be available as a priority to people with mental health difficulties, as well as other people with disabilities.

The National Economic and Social Forum's report in 2000; "Social and Affordable Housing and Accommodation, Building the Future…" recommends the establishment of a National Housing Authority, which would have responsibility for a national housing policy. It also recommends "social housing policies to include provision for the special needs of particular groups, and the need for a continuum of responses from independent housing, sheltered housing and through to institutional care." None of the recommendations made have since been addressed.

50% of those surveyed had lost accommodation for financial reasons. 45% of the whole sample felt that their illness had been exacerbated by lack of adequate accommodation, and 27% had lost accommodation because of illness. The above findings demonstrate the impact accommodation difficulties may have on mental health. This could also affect recovery prospects, or staying well, for mental health service users, and may have a role to play in the "revolving door syndrome". These findings would also suggest that

providing housing should be a priority. Maintaining the current accommodation while a person is in hospital should also be a priority.

Recently the government has imposed a 20% social housing quota on all property development. This offers an ideal start to providing adequate housing for mental health service users and other vulnerable groups.

Recommendations

1. Further research should be carried out on the impact accommodation difficulties may have on mental health status, and the link between mental health and homelessness.

2. The National Economic and Social Forum's report in 2000; "Social and Affordable Housing and Accommodation, Building the Future…" recommendations should be implemented immediately.

3. A Task force should be set up, in collaboration with Simon, Cope, Threshold, the Western Alliance for Mental Health, Mental Health Ireland, the Local Authorities, the Western Health Board, and any other relevant agencies, to examine the situation of inadequate accommodation for mental health service users.

4. This task force should work to address this problem immediately.

5. A percentage of available local authority housing stock should be set-aside for people with disabilities, including mental health service users.

6. As recommended by "Planning for the Future" more supported accommodation should be made available for mental health service users by the Western Health Board.

7. As a voluntary body not having statutory responsibility for the provision of housing, Mental Health Ireland is to be commended for their work so far in this area, and their approach be adopted by other agencies with statutory responsibility.

8. A specific officer for people with mental health difficulties, who is recognized by the local authorities, should be appointed, to represent clients in need of housing with the local authorities.

9. A peer advocate should be appointed to assist and support users in addressing accommodation needs, in particular to ensure that current accommodation remains secure while the user is an inpatient. He/she could liase with the above-mentioned officer to represent users' accommodation needs.

10. Transition or stopgap type accommodation should be available to users who may have lost accommodation while in hospital.

Discussion

DISCUSSION

" The point is we are not rocks. Who wants to be one anyway, impermeable and unchanging, our history already played out."

John Rosenththal

In the current climate of universal dissatisfaction with health services there is much to celebrate in the results of this report. Despite almost daily media reports of waiting lists, under staffing, poor facilities and inadequate investment throughout the health services at these were not the 'hot issues' for participants in this study.

Overall, respondents were satisfied with the facilities, staffing and the existing services being provided by the West Galway Mental Health Service. They are primarily dissatisfied with the way services are being provided rather than what is being provided. The recommendations in this report do not involve major structural changes or financial expenditure but may be even more difficult to achiever as they will require a sea change of public and professional attitudes and the development of a more creative flexible model of practice.

AIMS

The aims of this project were twofold:

⊄# To facilitate empowerment of service users
⊄# To evaluate existing services and inform future developments

FACILITATING EMPOWERMENT OF SERVICE USERS
The process
The group came together without any previous knowledge of each other, but through the process of sharing our stories, and experiences of the services, we learned to work well together. We were all service users in this process with no previous involvement in this form of research. We received a general outline and we used our own initiative to structure the project. Until we mapped our experiences we had no clear idea what direction to take. We felt the project was taking shape when we mapped our Pathways and this influenced the form our research took by giving us an outline for the questionnaire.

Reliving our experiences was painful but the most valuable part of the process. We found that we had a lot in common and by sharing our memories of traumatic life events, we learned to trust each other. Together we developed an environment of openness, respect and honesty through sharing our ideas, thoughts and feelings with each other. It was tough going at times, however a touch of humour was an important ingredient. We learned not to take ourselves too seriously.

Expressing the difficult emotions that arose as we talked about our experiences was very liberating for us, and allowed us to get past them and move on. Working through our feelings without fear of rejection by the group allowed us to focus more objectively. The group developed a strong sense of cohesion and felt confident enough to assume ownership of the project. The feelings of empowerment that we developed allowed us to work as equals with the professionals on the research team. As time progressed the boundaries between the facilitators and the service users disappeared and we worked as a united team.

We learned as we went along from different people's styles and approaches and individuals quickly assumed varying roles in the group. People were able to bring their own skills to the group from different fields of knowledge. It quickly became obvious that different people had their own favorite themes, and ensured that these subjects got sufficient attention in the questionnaire and written report.

PRACTICAL OUTCOMES

The project enabled and empowered service users in the group to venture into other avenues:

- Three of the research team are founder members of a User Led Drop In Centre (Cruinniú) for people experiencing from mental health difficulties – the first of its kind in Ireland.
- A number of service users have just completed Peer Advocacy Training (accredited with Open College Network, Northern Ireland.)
- The Pathways team made a submission to the Health Strategy as part of the national consultation process.
- Three members attended a user subgroup of the Mental Health Patient Care Accreditation Group (Western Health Board).
- A service user in the group has just been offered a position on Research Advisory Committee of the National Disability Authority and has been invited to become a member of the Mental Health Strategy Working Group (Western Health Board)

The fact that the members are venturing into other areas identifies Pathways as a mother project, from which we have learned, grown independently, been valued, supported and nurtured, held up as people of importance. It is hoped that this mother project that will give birth to other exciting new user-led initiatives.

RECOVERY

Reflecting on our experience of our process involved in carrying out this research, there are major similarities between our experience and the factors that influence recovery as described by Turner-Crowson and Wallcraft 2002 as outlined in our introduction.

EVALUATING EXISTING SERVICES AND INFORMING FUTURE DEVELOPMENT

To date, the Mental Health Services have been based on the medical model and the presumption that staff posses the expertise service users need for recovery. This model may have something to offer in physical medicine but is wholly inadequate when it comes to addressing the myriad difficulties associated with mental health problems. The need for an alternative model of practice is reflected throughout our findings.

 "The adherence to a narrow medical model that relies on diagnosis and obscures the whole person living within a context is viewed as antagonistic to growth and development" (Bassman, 1997).

The inadequacies inherent in the medical model underlie most of the recommendations made in this report. In this discussion we draw on relevant research and use the results of this report to answer two important questions rarely considered by proponents of the medical model.

- Who are Mental Health Service Users ?
- What do they want?

WHO ARE WE?

Sample Profile
As a result of this study, we can start to build a profile of service users and their experiences of the mental health service. In this sample, respondents had been involved with the service for a long time, were predominantly single and dependant on social welfare. The majority were young and unwell for one to ten years before contacting the service. Despite being fearful a sizeable proportion of respondents were alone when they first accessed the service. Every respondent attended the psychiatric unit in the general hospital and a large proportion was admitted to hospital. The majority felt information about their illness and proposed treatment was not adequately discussed with either them or their families and only a small proportion had any involvement in their treatment planning.

This sample profile immediately raises some serious questions:
- Are these findings likely to be replicated nationally?
- Are people with mental health difficulties more likely to be single ?
- Are they more likely to be unemployed?
- If yes, are these factors part of the cause or the effects of their mental health difficulties?
- Why is there still so much fear surrounding mental health services ?
- How can we dispel this fear?

WHAT DO WE WANT?

" The greatest mistake in the treatment of disease's is that there are physicians for the body and physicians for the soul although the two cannot be separated" Plato

In the new Health Strategy (2001) national goal three, objective one states " *The patient is at the centre in planning care delivery"*. Our findings would suggest that far from being the centre in planning care delivery, most service users were excluded from this process entirely. From First Contact to Aftercare the recurring themes are a desire to be informed and involved in the treatment process. These needs are interdependent as meaningful involvement requires information but information alone does not guarantee that service users will have meaningful involvement. Collaboration is key to placing the service user at the centre of the planning process. Frank et al (1995) proposes that the doctor is the expert on the disorder and its treatment, but the user is the expert on his or her own disorder and experience with treatment

COLLABORATION

We found little evidence of collaboration throughout the service from the acute unit through to day centres and training centres. Both users and providers are paying for this lack of collaboration in different ways and with varying consequences. As the treatment most participants had experienced was medication we choose the findings from that section to clearly illustrate the absence of a collaborative approach and the possible consequences.

MEDICATION

Despite the recommendations made eighteen years ago in *Planning For the Future* (1984). *" as most illnesses are psychoneurotic or psychosomatic, they require the more elaborate kinds of diagnosis and management, including psychotherapy"* and presumed progress in the understanding of mental health difficulties, 98% of the sample were prescribed medication.

Although most of the sample were agreeable to taking medication respondents wanted options such as counselling instead of or in conjunction with drug treatment. They wanted more information from staff about the drugs they were being prescribed instead of relying on drug company leaflets. They wanted both the benefits and side effects to be equally explained. Many participants stopped taking their medication at some time without medical consultation because of distressing side effects.

The lack of input service users had in planning their drug treatment is mirrored throughout the service. There are widespread reports of respondents feeling poorly informed, pressured into treatment and ignored/excluded. The current system undermines trust and precludes honesty as evidenced by the number of service users who abandoned

their primary form of treatment, medication without first discussing it with their doctors. If staff are selective about the information they provide and dismiss the concerns of service users it is to be expected that in turn service users will choose what to disclose to staff.

"*A good relationship between doctor and patient increases the willingness of the patient to take prescribed medication.*" (Schizophrenia Ireland Conference 'Whose Illness is it Anyway?'2000).

THE THERAPEUTIC RELATIONSHIP

The importance of the relationship between service users and staff cannot be underestimated and the quality of these relationships can determine how service users engage with the service. As the primary point of contact and the perceived authority within the mental health services doctors aroused the strongest negative feelings amongst participants who had not felt heard or acknowledged. It is important to note that although other staff were perceived less negatively, the relationships with staff in the activities dept, day hospital, day centre or training centre were not more collaborative than those with doctors.

Much of the inherent discord that exists between patients and clinicians lies in the fundamental difference between the users'subjective experience of illness and the clinicians approach to the disease (Sayre 2000) As service users are not considered by clinicians to be important informants (Razp et al 1993), it is difficult to see how the gap between what clinician and service users believe to be important can be bridged.

To begin we must establish what service users want from professionals. This study revealed a widespread desire for more counselling/ talking therapy while a three year in-depth report commissioned by the Mental Health Foundation identified what service users found most helpful was not medication but accepting relationships.*(Strategies For Living*, Faulkner, 1997) It is gradually being accepted that "*listening to mental health service users and providing opportunities for them to tell their unique stories are important empowering strategies."(*Campell &Shraiber 1989, Razzort 1995, Corrigan &Gorman 1997)

CARE IN THE COMMUNITY

The lack of sociological research is disappointing but not as disturbing as the absence of research conducted by the mental health services. The last comprehensive study *Planning For The Future* was carried out eighteen years ago and was emphatic about the importance of developing community services for the treatment of mental health difficulties. The report defines a community oriented service as

> *'a service providing a full range of treatment to persons with psychiatric problems with minimum disruption to their normal way of life'*

This definition implies that most users should not be admitted to hospital, and that treatment services should be delivered to them in their normal social environment.

Despite these recommendations and the economic boom Ireland has since enjoyed all the participants in this study were first seen in a hospital setting .A large proportion were also admitted to hospital on first contact with the services. This was issue was also addressed eighteen years ago in *Planning For The Future*(1984)

"*the fact that the premises in which the clinics are held are not identified solely with the treatment of mental disorders is undoubtedly great encouragement to persons to attend who might otherwise fail to seek treatment if it was necessary in the first instance to go to a mental hospital*".

It is no surprise that participants were unwell for so long before going for help. Many had their worst fears (being admitted to a psychiatric hospital) realised when they eventually made contact with the services.

In the interim it is difficult to see that any progress has been made in implementing these recommendations. According to the Report for the Inspector Of Mental Hospitals 2001 users admitted to hospital now spend shorter periods in care but the number of readmissions has increased. In a recent report the primary treatment offered was in-patient care (68%)(Finnegan, 1999). If we also consider that in 1996 you were almost four times as likely to be admitted to hospital for the first time for schizophrenia if you were in the unskilled manual category than if you were a professional (*Inequalities in Health in Ireland- Hard Facts, 2001*) it is clear that we are no closer now to an integrated community mental health service than we were twenty years ago.

BALANCE OF POWER

What is less clear is what service providers expect from their relationships with service users. How do the attitudes, assumptions and beliefs of service providers impact service users? The imbalance of power between professionals and service users needs to be acknowledged. The impact of this power differential and the contradictory roles of caring and control on the therapeutic relationship must be recognized. "*Good practice is about recognising this power and avoiding it by making the relationship as collaborative as possible. (The British Psychological Society p61)*.

The Connecticut Mental Health Centre (1992) research into collaboration concluded that consumers had significantly more interest in collaborative treatment than providers thought they did. They also found that most providers did not believe that their own lack of training in collaborative planning was a barrier (5%) while 28% of consumers believed they would need training. If the need to maintain power and control is a priority for

service providers, it is highly unlikely that collaborative models of care will even be considered.

THE NEED FOR RESEARCH AND DEBATE
"At any one time one adult in six suffers from one or other form of mental illness. In other words mental illness is as common as asthma." (Frank Dobson MP Secretary of State for Health 1999)

Mental health is an issue for all of us. It may not directly affect us, but we are guaranteed that someone amongst our family our friends or in our community will experience mental health difficulties. If we accept that there can be no health without mental health, then we all deserve treatment based on extensive investigative research, extensive debate and proven best practices.

Unless society as a whole starts asking some hard questions and demanding answers we will continue to have the type of service described by Professor Phil Barker speaking at the Schizophrenia Ireland Conference 2000,

> *"I think there is possibly no trade more pessimistic than the trade of psychiatry… I dream about a service which has got clear exits which show the way out of the system back into the real world."*

The Future

> *"When people not used to speaking are heard by people not used to listening then real changes can be made."*

This report is a testament to the fact that service users have a huge amount of expertise to offer in terms of their own care. We have now spoken out on what works for us within the current system including recommendations for change. This expertise can be acknowledged and integrated into the practice of service delivery.

This project is an example of the practical power of collaboration between service users and professionals. Each member of the group brought their own personal expertise to the process. Our future vision of a mental health care system is the acknowledgement and integration of this expertise into service development.

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Appendices