Pathways report: experiences of the East Galway Mental Health Services from service users perspectives.

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East Galway

Pathways Report

Sponsored by The Western Health Board

Experiences of The East Galway Mental Health services from Service Users' perspectives
Experiences of The East Galway Mental Health services from Service Users' perspectives
Authors

Pathways team

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Jane Maher.

Ger Lohan.

Anne-Marie Flynn.
Acknowledgments

For all the support given during the entire process.

To all of the Service Users who took the time to take part in this survey. Your experiences told this story.

Dr. David S. Evans, Senior Research Officer, Dept of Public Health, WHB.

Mr. Ray Sweeney (Director of Nursing, St Bridgid's Hospital), WHB.

Noel Brett (Regional Manager, Mental Health and Services For Older People), WHB.

All the Nurse Managers who made their centres available when needed for interviews and much more. With a special thank you to Mr. Gerry Tully (Manager, Loughrea Community Workshop) and Mr. Martin Staunton (Manager, Creagh Workshop, Ballinasloe)

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Foreword

For too long the voice of our service users has been silent. They had no outlet, and sometimes in the past no one was really listening. The service provider knew best and no other opinions mattered. However, since the early nineties the experience of our service users has been acknowledged at a national level as having a very important role in contributing to the development of their service.

The East Galway Future Shape Group in directing its planning process required service user input to ascertain levels of satisfaction and dissatisfaction with the present service. The experience and care in a rural population differs somewhat from an urban setting, access to care may be difficult because of the geographical area.

Having recognised the value of the service user research in West Galway - Pathways Report 2002, it was decided that a similar research project would have a valuable input to the developing service in East Galway Mental Health Service. Thus the East Galway Pathways Research Project came about.

This project was service user led-and service user focused. The project was also facilitated by service users who had achieved a level of expertise in research methodology following their experience in West Galway. Their time, care and attention to detail must be commended.

Important considerations have been identified in relation to service user education relating to their diagnosis, their treatment plan and medication. They identify the need for a high standard of accommodation in the hospital and community setting with access to accredited training programmes and employment opportunities. The need to direct our resources to care in the community is most important so that it supports our service user to achieve their full potential.

I thank the research group for achieving their purpose giving a voice to our service users. We are challenged and energised by the findings and will continue to work with our service users in developing and delivering a high quality mental health service.

Frank Murphy
AV/Regional Manager
Mental Health & Older People’s Services.
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John

My name is Johnny Wynne. I have been a service user since 1988. I have been attending the Training Centre in Loughrea since 2001. When first asked by the manager of the centre, Gerry Tully to join the Pathways team I said "no" as I did not know what it was about, but when Gerry explained that it was a survey conducted by service users for service users' he thought I would be able to contribute usefully to the survey. I became part of the Pathways team. I have learned so much about the needs of other service users and so much about myself. I have learned to listen to other peoples' views and ideas and to accept them and have worked with a wonderful group of people.

While we didn't always see eye to eye we worked through our difficulties and ironed out our problems for the good of the Pathways project. I have made very good friends in the group as they are wonderful and honest people and have worked hard on this project. At times it was not easy, at times it was stressful but we have seen it through to its conclusion. I would like to wish each and every one of them well in the future. I needed Pathways a lot more than Pathways needed me and I feel it has benefited me greatly and I hope that in some small way I have made a contribution to the East Galway Pathways Report.

Cathleen.

I have been an East Galway Mental Health Service User since 1995 and in that time I have experienced a lot of things in the service that were very good and some, not so good, (approx' 90% good and 10% bad). Therefore I was delighted to be given the opportunity to have my opinion and the opinions of other service users' considered by the Service Providers in the future shape of the mental health service. As a direct result of being part of this Pathways team I became a member of the "Future Shape" steering committee, which will advise on the shape of the mental health services for the future.

I was very pleased to hear at a two-day conference in October of last year that the service user is to be at the centre of all future plans for the mental health service. It has been widely agreed in the "Future Shape" group that the way forward is through direct consultation between service user and service provider. Needless- to-say, our Pathways team are in complete agreement!

I honestly believe that service users' have a lot to contribute to the formation of our mental health service in the future and I hope and pray that this Pathways report will play a major role in bringing about the changes necessary to make the Western Mental Health Service a role model for all other health boards in the country. I believe that this Pathways project should be carried out throughout the country.
**Personal Notes**

**Sean**

When asked if I would work on Pathways again in a supervisory role I was delighted to meet the challenge. I knew I would be passing on the skills I had learned to another service user group. However I did not realise how difficult a commitment it would be. Right from the start lack of money and time meant we could not design a new questionnaire. Compared to West Galway there was no process of "Mapping our Pathways" and no support group. This meant the bonding of the team was slower.

Even with all the goodwill we received lack of basic tools e.g. no computers, no telephone or photocopying facilities, did not help make this task any easier.

One positive result of the process was the lesser input from professionals compared to the West Galway Project.

Again I have made new friends. I hope I have helped to empower them. I wish all the team the very best in the future.

**Louie**

Whether it was jet lag (I had just returned from Australia) or whether it was the fact that East Galway Pathways was going to be run differently to the West I am not sure, anyway I fought with every member of the team at my first meeting.

East Galway Pathways was for me a new venture. There were problems undreamed of in the West Galway project. Problems such as the huge rural nature of the area, problems in that only one person had e-mail, only two had a computer, and problems of trust and training. I had to be reminded again and again that most of the core members were new to research and to be patient as others were with me.

It was clear from the start that this process was going to be totally different from the one in West Galway. It would stand on its own merits.

With regard to the people surveyed, they are a far older generation than in the West. Indeed, one man who returned his consent form but was not interviewed was 86 years old. These findings restate our worry about the lifelong nature of mental illness and the problems of lifelong dependency.

What I have taken away from this project is that I have to learn to listen. That people do not see things the way I see them. I have learned to accept this.
Jennie

My name is Jennie. I have been a service user since 1998. I am a recovering chronic alcoholic and in that year went into St. Bridgid's Hospital in Ballinasloe to detox. I cannot remember much about my first admission but I was there several times. The following 3 years I spent in aftercare with Liam Curley, Mary O'Connor and Martin Stack. These people saved my life. I was too ill to work so I attended the Creagh Training Centre Ballinasloe. The manager Martin Staunton and his team helped me back on my feet. I owe them a lot of gratitude. With time and care they helped me feel like a human person again. Gradually I regained my sanity, confidence and self-respect. I have a lot to be thankful for.

I am on the Rehabilitation Sub-Committee in East Galway Area. I was also a chairperson of the service users committee for a while at the Creagh Training Centre.

When I joined Pathways I was apprehensive but as I got to know everyone I came out of my shell. I have gained a lot since joining the group and formed great friendships with the team. I wish them well and hope that the pathways report is a great success.

"Rehabilitation means making the best of the present and foreseeing a good future"

Quote from New Zealand recovery model. This is my pathway to recovery.

Mary

When asked to take part in this research last February, it seemed a good idea and long overdue. Such a survey had already been completed in West Galway and we worked on that as a guideline. A lot of changes had to be made to suit East Galway. Although my input was minimal in comparison to other members of the team, everyone was encouraged to contribute and we worked as a team. A lot of hard work has gone into this report and I hope it will bring about much needed change in our psychiatric service in East Galway and beyond. My involvement has made me a more positive and stronger person. I wish all the members of the East Galway Pathways Team all the best for the future.
Jane

My name is Jane Maher; I am a service user in Toghermore Training Centre in Tuam since 16th of November 1995. Ironically, I have achieved no training degree, due to personal illness, which made me lose jobs prior to Toghermore e.g. Civil service and shop assistant. The latter told me to resign. In good health I have always looked for goals and after four years I left Toghermore training centre and applied to the National Rehabilitation Board in Dublin to study as a nurse’s aid. I didn’t last at it. After four months I ended up in hospital again and was sent back to Toghermore. These have led to nervous breakdowns, lack of confidence, fearing the future and future employment/courses.

When in good health I do work experience and like to learn new things. I see Pathways as a challenge and like the effort we make as a team. I have made a lot of good friends too. It has given me back some of my self-confidence and I hope it leads to other things. I can do with the camaraderie of the group I am with. One of the things I would like to see changed is the removal of stigma from mental illness. From the start people talked of their past and you felt that you were not alone.

The service users in Pathways were good listeners, encouraging, reassuring, friendly, supportive and enthusiastic. There was a lot of brainstorming and debates. I was looking to achieving goals as a group, communication, patience and people who had a positive outlook. Firstly it was daunting but I soon found my stride in the group and felt proud to be in it. I felt more confident in my abilities. Everyone was wonderful. I would like to thank you all for the support and friendship. I feel that I have achieved something worthwhile.

Ger

Earlier this year, Michelle Hardiman, Nursing Officer came to me and asked if I would be interested in going to a meeting in a house in Mervue, Galway. People from different parts of the county as well as members of the West Galway Pathway’s team were there. It was there that the East Galway Pathways team was formed.

I was delighted to get involved. I had no idea that such a group existed. I could tell someone about the way I have been treated and used. My voice would be heard at last. “Pathway’s” is the voice of the mentally ill. The stigma of a psychiatric illness cuts you out of society. I was not used to the type of work involved, but all that was required of me was my opinion. As time went on we came to know each other well and I got more involved. I now feel more confident in myself and in what I do.
Pat

I didn't know about the Pathways Team until I was nominated by the staff of Creagh Training Centre. I didn't know what it was about. It took a few weeks for me to understand. The people on the Pathways team helped me to know what the team was about. I am enjoying being in a group with lovely people.

Now I want to talk about isolation of service users. There are service users who are isolated, because their families, neighbours and friends would not talk to them. They do not call to see, how they are getting on. These people would not ring the service user and talk to them. Furthermore the families, neighbours and friends would be talking about the service user behind their backs and giving them bad looks. The result is that service users would be down and lonely in themselves. This causes stigma and could result in service user committing suicide or harming themselves.

Anne-Marie

My name is Anne-Marie. When I read the West Galway Pathways report after it's launch, I was very impressed with it's honesty and insight into the mental health services in the west from a service users perspective. I felt a report like this was long overdue and I was delighted to be asked to be part of a similar group in East Galway. Attending the Loughrea Training Centre at this time I progressed to a third level education and a Foundation course for a year in GMIT. Having successfully completed this course I am now pursuing a degree course in GMIT. The manager and his team at the training centre helped me a great deal along the way and are to be commended. Although I only remained eight months with the research team I found my time with them both a challenging and rewarding experience. I admired the team and the interviewee's honesty (through the tears and the laughter) as each member had their own personal experience about the services. I hope this report will bring about much needed improvement within the service in East Galway especially for the service users themselves.

Thank you to other members

Michael Moran
Brendan Morris
Shane Hourigan
Aubrey Tully
Executive Summary

Introduction

East Galway Pathways research project explored 34 service users experience of the mental health services in the East Galway service region. The research was conducted, designed and completed by a core team of East Galway service users. They used the assistance of expert research professionals and help from staff members. The research took a year to complete. It involved lengthy interviews with 34 service users who were involved with the mental health services during the period June -December 2002.

Main Findings

1) **Demographics:** In the sample we found that contact with the services was lengthy and began early in life. 9% had used the service for over 40 years. 61% were single and 71% of the sample was in receipt of social welfare. 32% have only received primary education.

2) **First Contact:** 18% were ill for one to five years before accessing the service. 18% went alone to seek help. 56% were fearful of service on first contact.

3) **Diagnosis:** 73% of the sample stated they would like more information on their diagnosis.

4) **Contact with Professionals.** This section held professionals in good regard. There are questions to be asked whether there exists a multi-disciplinary team.

5) **Medication:** 100% of the sample was using medication treatment as primary care treatment. 40% of respondents stopped taking medication without prior doctor’s consent.

6) **Electroconvulsive Therapy:** 44% of the sample was prescribed E.C.T. 94% of these respondents had it. 71% of these will never take the treatment again.

7) **Counselling:** 77% of the sample found counselling to be helpful. 71% would like to use it again. 45% of the counselling service received by the sample was from nurses.
8) **Activities in Hospital:** Two-thirds of the sample attended activities in the hospital. 80% of these respondents stated these activities were helpful in their recovery.

9) **Crisis in Hospital:** 23% of sample had a crisis in hospital. 2-12 hours was the time waited for the crisis to be dealt with by doctors.

10) **Preparation for Discharge:** Over half 54% were not involved in planning of their discharge from inpatient psychiatric unit. 36% of respondents self-discharged themselves.

11) **Privacy:** Fewer than half the respondents found their need for privacy in the psychiatric unit was adequately met.

12) **Crisis in the Community:** 33% went to the local hospital for help in a crisis. 18% of the sample went to casualty.

13) **Day Centres:** 100% of respondents attending Day Centres found out about them from the medical profession.

14) **Training Centres:** 44% of respondents attended training centres. 40% did not receive a recognised qualification and 54% did not look for work related to their training.

15) **Transport:** 73% of respondents attending training centres/day centres travelled under a quarter of a mile to pick up/drop off point by transport bus.

16) **Employment:** 64% of respondents were long-term unemployed at time of survey. 92% of sample stated employment was important to them. 71% of the sample did not receive help in returning to the workforce.

17) **Well-being, Coping Strategies and Social interaction:** 94% of the sample regarded talking to friends as the most important coping strategy. 77% of sample stated that their illness had a negative impact on their confidence and self-esteem.

18) **Housing:** 12% of the sample had experienced homelessness after using the mental health service. 25% of the sample reported that they had lost accommodation due to their mental health difficulties.
Executive Summary

Recommendations

1) There should be a concerted and collaborative effort made by all stakeholders to identify and address the negative factors that prevent early contact with the Mental Health Services.

2) Effective public awareness of how to access services and support available should be promoted by service providers.

3) A sensitive and supportive method of informing service users of their diagnosis needs to be implemented immediately.

4) A Multi-disciplinary team approach must be introduced across all catchment areas to provide equity of service delivery.

5) Considering the fear that E.C.T. provokes and the limited benefits reported: (a) this treatment requires research to justify its continuing use. (b) service users should fully understand and have informed choice on all aspects of this treatment.

6) Counsellors should be employed as a matter of urgency in the mental health services and training for nurses in various counselling approaches such as cognitive behavioural.

7) Every inpatient should be informed about the purpose and structure of each activity and should decide and plan their own activity programme.

8) The time waiting for crisis intervention after hours in the inpatient psychiatric unit should be reduced.

9) Every service user should be involved in the planning of their own discharge from the hospital. This plan must address specific concerns of the individual service user taking into account social and psychological needs.

10) Service users should fully understand all aspects of their drug treatment and other forms of treatment should be offered instead of or in conjunction with medication.

11) All aspects of privacy in Western Health Board facilities should addressed for equity. In designing the new unit in Portiuncula for East Galway, care must be taken to prioritise privacy needs.

12) There should be clear guidelines as to where service users go in time of crisis in the community. Recruitment of accident and emergency liaison nurses would reduce casualty waiting times.

13) Planning and involvement of their own activities programme should be an integral part of service users treatment at a Day centre. Review and evaluation should be built into activity plan.
Executive Summary

14) There are no recommendations with regard to transport to day centres and training centres. The vast majority are happy with it.

15) If only a foundation course is available at training centres, these courses must have a goal. Individual assessment, goal setting, regular review and service user feedback must be included.

16) An multi-agency approach needs to be adopted to deal with service users employment issues. Further research is needed. We recommend separate interagency study on employment, training and education needs of service users.

17) The importance of individual coping strategies should be acknowledged, encouraged and where possible, incorporated into the mental health service based on the recovery model.

18) Long-term appropriate accommodation is essential for service users. This should be a priority for all agencies involved.

Conclusion

The findings and recommendations listed in this summary provide a brief overview of the existing difficulties in the mental health services and possible solutions. In essence, both the problems and solutions are based on communication between service users and service providers. Service users should be fully informed about all aspects of their treatment, given the opportunity to ask questions and express concerns and ultimately be allowed to make their own decisions where capable and have those decisions respected. It is clear from this study that mental health service users have expertise and desire to be active participants not passive recipients of treatment in the mental health services.
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 the second Pathways report, a Service User-Led Survey of people's Experiences of the East Galway Mental Health Service in 2002. This introduction will set out the reasons why this project was necessary and how we did it. The first Pathways project was carried out in West Galway by a group of dedicated service users in conjunction with Schizophrenia Ireland and sponsored by the Western Health Board.

As the West Galway report had been so successful and had provided such useful information, the Western Health Board requested that one should be carried out in East Galway. This request was made to the West Galway Pathways team who decided that they could not carry out such a request without East Galway service user participation. The East Galway Pathways team was born as a result.

The research team members were sourced through personal contacts by members of staff in each mental health service area; these included Portumna, Loughrea, Ballinasloe, Mountbellew, Toghermore and two West Galway Pathways members who had the experience to guide this new group. In total we had 11 members.

This report explores the experiences of thirty-four service users who availed of the mental health service during the period June to December 2003. As in West Galway it was agreed that a Participatory Action Research (PAR's) approach should be adopted.

GOALS OF PARTICIPATORY ACTION RESEARCH (PAR)

PAR epitomises four main research goals:

1. Empowerment;

For too long service users' have been without voice, ill informed and dictated to in a well meaning manner. It is our aim to change this, to seek more input for service users' by involving them into the formation of the mental health services.

2. Supportive relationships;

The role of carer to the service user must be given much better support from the service provider with consent from the service user. The service providers should promote peer advocacy and self-help groups. It is important for service users to be empowered after acute illness and to be regarded as equals in this caring relationship.
3. Social change;

It is the aim of this Pathways group to enlighten the general public about mental ill health. It is also the responsibility of the service provider to do likewise. Disability should not be seen as inability as proven by this group with this research.

4. Learning as an on-going process.

The Pathways group gained new skills and learned about Participatory Action Research during this project. We have no intention of ending this here. This is the beginning of strengthening the voices of service users. For this type of project to work, we recognised that all those involved must be willing to accept and promote the possibility of recovery for themselves and for others.

5. Person centred approach

With such limited research in this area the Western Health Board are to be congratulated for their willingness to fund this second very worthwhile project. This implies an acceptance of the need to place service users at the centre of service development and willingness by the provider to embrace change and engage with people who have traditionally been excluded and voiceless. This is only the second research project of its kind in the Western Health Board area and indeed in this country. A truly innovative aspect of the research has been the Health Board's willingness to enable users of the service to decide for themselves how this research should be designed, conducted and presented.

6. Aims of the Research

The aims of this project were twofold:

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

Coupled with these aims, there is the vision statement in the Health strategy 2002 that states:

"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". (Department Of Health And Children, 2002)

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 towards the achievement of these welcomed goals. This research is a practical outcome for both the aims and vision statement to be realised.
METHODOLOGY

Background to current project

The 1st Pathways Project "Experiences of West Galway Mental Health Services from a Userled Perspective" was launched on World Mental Health Day, October 10th 2002.

At a Western Health Board Strategy Group for Mental Health Meeting in November 2002, Mr Noel Brett, Regional Manager, Mental Health and Older Peoples’ services, announced that his department were interested in a similar project being carried out in East Galway. This project would inform both the work of the strategy group and that of the Future Shape Project (a group of committees overseeing the move to the community in the context of the closure of St. Bridgid’s Hospital, Ballinasloe).

Design of Project

Meetings took place in January 2003 with the Development Officer For Mental Health Ireland (Helen Dempsey) and West Galway Pathways Team (Louie Maguire Sean Collins and Liz Brosnan) to work out the similarities and differences between the two projects. It had been suggested that the West Galway Pathways Team could undertake the project in a different location, namely East Galway, and using the same procedures. However, the team were not happy with this approach, since it did not recognise the differences in services in the two areas and did not provide an opportunity for service users from the Eastern area to benefit by becoming involved. The Development Officer suggested an alternative approach as follows:

Two original team Members (Louie Maguire and Sean Collins) would now be in a position to act as trainers or ‘consultants’ to the new project, allowing them to pass on their skills and experience. Helen Dempsey (Development Officer, Mental Health Ireland) and Liz Brosnan (Research/Resource Officer, Western Alliance for Mental Health) would act as a support to both the trainers and the new East Galway team. This solution seemed in keeping with the ethos of the project. It would also best suit the situation given time and funding restraints. We developed a draft proposal around this framework and submitted it the Department of Mental Health and Older People.

Building the Team

Over the next number of weeks a group of 12 gradually emerged. Two venues for weekly meetings were arranged with the support of local training centre managers Gerry Tully (Loughrea) and Martin Staunton (Creagh, Ballinasloe). A schedule of twice weekly meetings was set up, the principal task being to amend the original West Galway questionnaire on the services and service users own experiences to suit East Galway. This was a time consuming process. The Development Officer attended some sessions in an advisory and supportive capacity. Outside assistance from Dr. David Evans, Dept. of Public Health and Roisin Flanagan was sought around questionnaire design. There was a desire to improve the earlier version in terms of efficiency.
Methodology

Because the roles of the West Galway service users were not made clear, the East Galway members were of the opinion that the West members were only there to be advisors to the East Galway team. However the role of the western members changed because of their experience and a greater input was asked of them. The West Galway members now became co-ordinators and the team settled down to work.

Designing the questionnaire

The most important part of our early work was the designing of a suitable questionnaire to obtain as much information as possible in a friendly manner from East Galway Service Users. The team decided to adapt the West Galway questionnaire to suit the services in East Galway. These services are made up of a long-stay hospital, an acute unit, an alcohol unit, three training centres and a number of day centres. We removed one section and added a new section on transport to day centres and training centres due to the large rural area that is East Galway. Although we knew that the questionnaire would take a long time (one and a half hours) to complete, because of service users' different experiences extra questions were added to give a more complete view of the whole East Galway mental health service.

Sample selection

A random selection of 400 names was selected by Ms. Helen Dempsey (Development Officer, Mental Health Ireland) from a database of 1200 supplied by Mr. Ray Sweeney Director of Nursing, St. Brigid's Hospital and community based nurse managers of all the different service centres in the area. The sample had to be out-patients who used the services between the periods June- December 2002. A consent form and information letter detailing the purpose of the study and by whom it was being conducted was sent to these 400 people. They were asked to return the signed consent form if they were interested in taking part in the project. Only when the signed consent forms were returned did the research team gain access to their names. Only 50 consent forms were returned out of a total of 400 (A response rate of 12.5%) of these 34 were subsequently interviewed.

Transport difficulties

This survey was constantly upset by team members transport problems. The average team members travel to a venue was a 60 km round trip. However due to the limited public transport system in the area some members spent 2-3 hours going to venues. Indeed one member at the first six months of the survey did round trips of 160km many times to help other members who had travel difficulties. Transport was also a worrying problem when the information days were organised regarding collecting service users for interviews.

Information days

The team felt that service users needed to be informed about this Pathways project in order to encourage a better response rate than in West Galway. It was decided to hold information days in all of the service centres in the area. Plans were made and posters were put up in each of the service centres detailing dates and time for these talks.
Notice were placed in each parish newsletter. The two members from West Galway spoke of their experiences in compiling the West Galway report and what changes had or had not come about because of their work. Two East Galway members spoke of their hopes and expectations for this project. They spoke of the importance of services users having input into their own mental health care. They also spoke of the service provider's willingness to promote change for the betterment of the services for all. We found that there was great interest from service users as a result of these information days.

Many of the service users asked could they be interviewed for the survey; however they could not, as this would not be regarded as a random sample for research purposes.

Interviews

Due to the large area that is East Galway, the interviews could not be held in one place. They were held in four different service areas, Loughrea, Tuam, Ballinasloe and Mountbellew. This took time and organisation. Appointments were made and interviews conducted over the months of July and August 2003. The team had detailed interview training from Roisin Flanagan and Helen Dempsey M.H.I. (research consultants to the group) that gave us confidence to complete our task.

Out of the 50 consent forms returned only 30 service users turned up for interview on the appointed days. Individual appointments were made for those service users who didn't show up. However only four extra interviewed resulted from these non-shows.

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:- in the course of designing our questionnaire, 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 service 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 service 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 Hospital: - 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 weekend leave, while others found this lacking. All agreed that aftercare was inadequate and needed to be addressed.

11. Crisis while in the Hospital: - this was included because some of the team had experiences of major problems with crisis management in the hospital.

12. Crisis in the Community: - for the majority of the group the only place to go in a crisis, outside office hours, was hospital.

13. Day Centres: - it was agreed to introduce a section on day centres because some of the core members attended day centres. Further, due to the closure of St. Bridgid's Hospital and the increased emphasis on community services we felt these centres would be of more importance in the future.

14. Training Centres: - the entire 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.

15. Transport: - Because of the rural nature of East Galway it is necessary for service users to travel to day or training centres.

16. Employment: - no core members of the group were in full-time employment at the time of the survey. This section was planned to explore the difficulties experienced with jobs and employers. It was agreed to examine the support offered to service 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 service users with their illness. The Pathways group found that isolation and stigma were highly negative influences on their recovery and it was pertinent to investigate how service 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 service users who were homeless leaving the hospital. 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 service users of the Mental Health Services.
Introduction

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

Main findings

Length of contact with services, age now, and age at first contact:

79% of respondents have been involved with the services for more than 5 years
47% for more than 15 years.
9% had used the service for over 40 years.

76% were over the age of 40
21% were over the age of 60
No one presented for interview under the age of 30.
Figure 2 Age at first contact

Figure 3 Marital Status
Demographics

**Figure 4** Employment status

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Time</td>
<td>21%</td>
</tr>
<tr>
<td>Part Time</td>
<td>21%</td>
</tr>
<tr>
<td>Home Maker</td>
<td>9%</td>
</tr>
<tr>
<td>Voluntary</td>
<td>9%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>13%</td>
</tr>
<tr>
<td>Job Share</td>
<td>3%</td>
</tr>
<tr>
<td>Retired</td>
<td>9%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Figure 5** Type of Social Welfare

<table>
<thead>
<tr>
<th>Welfare Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Allowance</td>
<td>68%</td>
</tr>
<tr>
<td>Disability Benefit</td>
<td>12%</td>
</tr>
<tr>
<td>Unemployment Benefit</td>
<td>9%</td>
</tr>
<tr>
<td>One Parent</td>
<td>9%</td>
</tr>
<tr>
<td>Contributory (Non) Pension</td>
<td>12%</td>
</tr>
</tbody>
</table>
Demographics

Figure 6 Area of Service Use

Figure 7 Educational Status
Demographics

Discussion

It is interesting to note that contact with the East Galway Mental Health Services among the sample is very lengthy. 9% of the sample had contact with the services for over 40 years. This questions the effectiveness of interventions by the services while also highlighting the long-term nature of mental health problems. First contact and indeed the onset of mental illness appears to start early in the lifespan. 56% were under the age of 34 when they first had contact with the services.

The marital status of respondents raised an interesting point. Over 61% described themselves as being single with a further 10% widowed separated or divorced. Given the fact that all of our sample was over thirty and also that 77% were over forty this raises serious questions on how mental health problems impact on intimate relationships.

We found that only 21% were in full time employment. We have to ask the question do mental health difficulties lead to unemployment or does unemployment lead to mental health difficulties? This topic will be dealt with further in the employment section of this report. Related to this are the high levels of dependency on Social Welfare. Seventy one percent of the sample was in receipt of welfare payments, this finding is similar to the Brosnan et al (2002) West Galway report at 70%. Almost 71% of these were in receipt of disability allowance/benefit. This is significant in the light of the fact that people on Disability Allowance/ Benefit are deemed unable to work and are often caught in a poverty trap. This in turn must have an impact on mental health.

Education of the service user in the survey is of concern as 32% only received primary level. The older age group of the survey suggests that service users had no other option but to leave education at an early age. This would be in keeping with the general lack of higher education among the population of rural Ireland when they attended school.

It is significant that 24% of the sample is living alone and a further 29% are living in WHB supported accomodation.
First Contact

Introduction

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

Main findings

First contact with services

We asked how long the service users were ill before coming into contact with the mental health services? 41% of the sample were ill for over a year before coming into contact with the services, with a further 44% who were ill less than 3 months and 24% who were ill between one and five years. We asked who informed them of the services? 82% of the sample were informed by their G.P. We then enquired if anyone accompanied them when going to the mental health services? Either a member of their family or a partner accompanied 51% of the sample. Eighteen percent of the sample went alone. We asked where the first point of contact was made? 70% were admitted to the local Psychiatric hospital on first contact.

Fear of service

We asked were the service users fearful of the mental health services on first contact? A total of 56% reported feeling fear of using the services. The comments below demonstrate service users perceptions of that fear:

- I was fearful of someone seeing me use the service
- I didn't know what it consisted of
- Unknown territory afraid because of films I'd seen and expected scenes from psycho
- I was afraid that I would meet someone that knew me, I was ashamed
- I was at a stage where I knew there was nothing else for me
- Yes. I didn't know what was ahead of me
- No. I was so depressed and felt inadequate to cope with life. I knew I would get help here
- In the morning a nurse took the sheets off the bed and I couldn't know where to go or what to do. I couldn't get my bearing right. I did my best
- No. People need to be told that they will get better and that there is light at the end of the tunnel
- They just dosed me with high doses of medication there was no therapy just sitting around smoking
First Contact

However, though the majority were fearful on first contact, 63% of respondents found their first contact to be the service to be reassuring. The following are some of the reasons why:

- Yes. I found it very helpful
- I thought that the doctor and the nurses were very good I couldn't complain
- I was able to talk things through to a nurse
- At long last I felt there was someone who understood me
- Glad to be getting help but upset with myself for letting people down
- I came away with the feeling that I was starting on the road to recovery

Treatment offered

We asked the respondents what treatment was offered at first contact:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>81%</td>
</tr>
<tr>
<td>Admission to hospital</td>
<td>49%</td>
</tr>
<tr>
<td>Counselling/Talking Therapy</td>
<td>32%</td>
</tr>
<tr>
<td>Others</td>
<td>7%</td>
</tr>
<tr>
<td>Referral to other professionals</td>
<td>25%</td>
</tr>
</tbody>
</table>

The table above shows that medication was prescribed rather than any other form of treatment on first contact.

Communication with service users and their families

We wanted to know if the illness was adequately discussed with the service user or their families. 57% of the service users stated their illness was discussed with them, while 44% stated that their families were not given an opportunity to discuss their illness. We further asked was the treatment plan adequately discussed with themselves or their families? 56% of the sample stated their treatment programme was adequately discussed with them while a further 53% stated their treatment programme was discussed with their family.
Recovery process

We wanted to know if the service users had any input into the planning of their recovery programme? 65% of the sample stated that they were not involved in the planning of their recovery programme. Comments on this recovery and first contact experiences are as follows:

- It took a long time to overcome my illness best part of two years before I felt relief
- I did what I was told. I believed that they would cure me
- I found it hard to get the information about the service
- A very confusing and misleading experience
- I used to fear the future
- Only for my first contact I would not be alive today

Access to the services

Half the respondents stated that the service was easy to access. A further 29% stated the service was moderately easy to access.

Discussion

Accessing the mental health services was very traumatic for people in our survey. 65% were ill for a year or longer before contacting the mental health service. Seventy percent were admitted to hospital on first contact: maybe this would have been lower if people contacted services earlier. Perhaps, one reason people did not contact the services earlier is fear. Fifty six percent were fearful of contacting the services. This is similar to the Brosnan et al (2002) West Galway findings in that almost 60% were fearful. (Brosnan et al Report 2002) These findings suggest that the general publics attitude to mental health prevents people from getting help. If earlier detection is not sought a mild mental illness can get worse without medical intervention. We must act to change this fear of mental illness and treat it as any other health issue.

Nearly two-thirds of the sample reported that they were reassured on first contact. This finding shows that with the help of professionals, the fear and isolation of service users can be reduced. There needs to be further awareness among the whole community on mental health issues. This can be achieved by better education on mental health problems, treatment and other support systems. Nearly two-thirds of service users reported that they were not involved in the planning of their treatment. 40% of the sample stated that their illness was not discussed adequately with them on first contact. As with other sections in this report involvement in treatment by service users should be a priority. It has been shown that this involvement by service users in the decision making leads to higher levels of satisfaction with services and greater self-efficacy (Holland et al 1981) (Chinman et al 1999)
A total of 44% reported that their families were not given an opportunity to discuss their illness. 38% of the sample reported that planning of treatment was not adequately discussed with their family. When service users want their families involved, it is crucial that the service providers make use of this resource given their caring role. This can be a life long illness, and therefore, families must be given all the support necessary to help them achieve a positive outcome. According to the World Health Organisation (2002) mental health professionals; families and family support organisations have a lot to learn from each other. Mental health staff can learn from families the knowledge, attitudes, and skills that are needed to enable them to work together effectively. Families in turn, benefit from learning a process of problem solving in order to manage the illness more effectively.

There needs to be increased awareness among the whole community on mental health issues. This can be achieved by better education on mental health problems, treatment and other support systems. Mental health difficulties may be a life long experience: therefore the service user and their families must be given all the supports necessary to achieve a positive outcome. If community care is to become a reality it is essential that service users with adequate support must begin to assume greater responsibility for their own recovery. It is also essential that proper structures are put in place to facilitate this recovery.

\[\text{Recommendations}\]

1) Emphasis must be given to early intervention in service users mental illness.

2) Service users must be involved in both the planning and implementation of their treatments.

3) Families must be given all supports necessary, advice and help in their caring role.

4) While we recommend family involvement, the level of this caring role should be decided by the service user.

5) Efforts must be made to address public perceptions of mental illness.

\textbf{The following should be considered:}

a) Public awareness campaigns.

b) School and colleges education awareness.
Treatment

* Diagnosis

* Medication

* Contact with Professionals

* E.C.T

* Counselling

* Activities in The Hospital

* Crisis in the Hospital

* Preparation for Discharge

* Privacy
Diagnosis

Introduction
In this section we were interested in finding the service user's source of diagnosis and their experiences of this. We were not interested in specific illnesses.

Main Findings:

Initial source
When asked about the initial source of their diagnosis, the main categories were:

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>26%</td>
</tr>
<tr>
<td>G.P.</td>
<td>22%</td>
</tr>
<tr>
<td>Self-education</td>
<td>12%</td>
</tr>
<tr>
<td>On a form</td>
<td>9%</td>
</tr>
</tbody>
</table>

As can be seen from the table above the psychiatrist was the highest initial source of diagnosis, G.P.s were second. A further 9% learned from a form.

Comments on this initial source were as follows:

- 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

Satisfaction with Diagnosis
We asked were the service users satisfied with the source of their diagnosis? A total of 55% of respondents stated that they were satisfied and 19% did not know whether they were satisfied.

Comments were as follows:

- 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.
- I think the doctors must have been right because a second doctor gave me the same diagnosis.

More information
We further asked would the service users like more information on their diagnosis? From the results 73% of respondents stated they would like more information. This is an identical figure to that found in the West Galway Study.

Comments on more information were as follows:

- Like to know how they got there.
- Was never explained to me properly about diagnosis.
- They were very vague, not to the point.
- First diagnosis was wrong and it wasn't explained what was wrong with me.
Discussion:

There were such a diverse range of sources from which people found out about their diagnosis, this suggests that standardised procedures are not implemented within the East Galway Mental Health Service. 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 service user. Although, 65% were informed within a year, a disturbing 21% were never informed at all of their diagnosis. Service users have learned of their diagnosis by such abstract sources as finding out from a sickness certificate, on a social welfare form or self-diagnosis. There are important implications of finding out on a form: lack of support, lack of opportunity to question or clarify and a missed opportunity to explore personal and family implications of diagnosis. Nineteen percent of service 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 service user or the perception that diagnosis is a negative experience. The level of satisfaction is difficult to measure.

At the very least, this section should highlight the necessity for the Mental Health Services to handle this issue openly, honestly and with a great deal of sensitivity and in a uniform manner across sectors/regions.

There is a distinct lack of information reaching the service user as 73% of the sample felt that they would like more information on their diagnosis. This is an identical figure to that found in the Brosnan et al (2002) West Galway Study. There was a strong desire among service 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 service user and their family are about their illness, the better they can cope. It is very important that the families of the service user with the service user's consent are kept informed about the service user's illness. Support during and after diagnosis is necessary to demystify the illness and empower the service user. Correct management of diagnosis may in future be perceived as a milestone towards recovery for the service user rather than a negative experience.

Recommendations

1. Provide a standardised set of guidelines for Service Providers to discuss diagnosis with service users.

2. Create a safe and supportive environment for addressing the feelings and queries of the service user regarding their diagnosis.

3. Ensure service users completely understand the personal implications of the diagnosis; eg, treatment, side-effects, prognosis, recovery, relapse rates.

4. Provide written information for the service user's reference on their diagnosis.

5. With service users permission, inform close family members of diagnosis.

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

7. Most importantly discuss recovery as a realistic opportunity.
Medication

Introduction
This section investigates service users experiences with prescribed medication and the extent to which medication is used as a form of treatment within the mental health services.

Main Findings
Prescribed medication
All the service users were prescribed medication as a form of treatment, with 91% currently taking medication. We asked if their medication treatment explained to them? Seventy-one percent of the sample understood why they were taking their medication. We further asked whether these prescribed drugs were explained to their families, carers, friend or advocate. Half responded that medication was not explained to their carer, partner, friend or advocate.

Agreeable to take medication
Eighty eight percent of the sample stated that they were agreeable to take medication. Of the remaining 11% who were not agreeable: 50% were agreeable after reassurance, 25% were pressured and 25% were forced.

Alternatives to medication
In this qualitative question service users were asked if they thought medication was the only option at the time. The majority believed that it was the only option.
- Depressed and elated, I needed something to control my mood.
- Yes, I had to take it to make you better
- Yes, I thought I might come out of the depression sooner by taking the course of medication.
- Yes, I think that the tablets prescribed should be taken.
- Yes, I was badly confused: I couldn’t think straight, medication helped me think.
- Yes I wasn’t offered anything else

There were only a few responses for counselling and talking therapy as an alternative therapy. Some commented that they were not aware of other forms of treatment:
- I was unaware of alternatives at the time which were available but not informed of it
- I believe that behavioural therapy would have helped me
Involvement in Planning Medication

We asked whether the respondents were involved in their medication plan; 65% of the sample reported they were not involved in their medication plan. We further asked would they have like to be involved in this plan; 80% of the sample reported they would like to have been involved in the planning of their medication treatment.

Stopped taking medication

A total 40% of the sample stopped taking medication without consent from their doctor. When we asked what the reasons for stopping were; half of those who responded mentioned side effects. Other reasons were alcohol related and being fed up with taking medication.

- I felt over medicated, having side effects both mentally and physically.
- I thought I could manage without it.
- Yes, Medication was slowing me down and depressing me.
- They were making me feel drowsy. A side-effect - weight gain
- When I was out drinking I would stop taking medication
- I thought that I was better and was experimenting.

Information on Medication

We then enquired whether information on benefits and side effects had been explained to them. Seventy percent of respondents reported that the benefits of medication were explained to them. Thirty-seven percent of the respondents reported that side effects were not explained to them with 10% stating that these side effects were only explained to them moderately.

The table below shows where the service users in the sample got their knowledge about their prescribed drugs from the following list they cited these results.

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>From Consultant psychiatrist</td>
<td>50%</td>
</tr>
<tr>
<td>From G.P.</td>
<td>37%</td>
</tr>
<tr>
<td>From Drug Companies</td>
<td>25%</td>
</tr>
<tr>
<td>From Books</td>
<td>25%</td>
</tr>
<tr>
<td>From other patients</td>
<td>19%</td>
</tr>
<tr>
<td>From Duty Doctor</td>
<td>16%</td>
</tr>
<tr>
<td>From Media</td>
<td>12%</td>
</tr>
<tr>
<td>From The internet</td>
<td>6%</td>
</tr>
<tr>
<td>Others</td>
<td>0%</td>
</tr>
</tbody>
</table>

It can be seen from the table above that the greatest proportion of service users obtained their knowledge of these prescribed drugs from the medical profession.
Discussion

These results clearly show the medical profession's heavy reliance on prescribed drugs as the main form of treatment to service users. Further, it shows that service users were compliant in taking these drugs. Yet, informed choice and alternatives to medication for service users appears to be lacking. The majority of service users did not have any involvement in the planning of their drug treatment, yet when asked would they like to been involved, 80% stated they would.

As 40% of the sample stopped taking their prescribed drugs without their doctor's consent, would involvement in their treatment plan prevent this happening? Although this figure is lower than the West Galway Pathways Report at 65%, it is still unacceptably high. Understanding these drugs and unpleasant side effects is essential, and may remove the fear and anxiety that prevent people taking their prescribed medication. According to the Zoe Petet-Zeman et al (2002) NSF U.K. (Don’t it make you sick 2002) the impact of side effects must be carefully assessed on an individual basis and medicine selected, monitored and where necessary changed accordingly.

If a medication plan is put in place with input from the service user, before they are discharged from hospital, then service users could take greater responsibility. It has been clearly shown that if service users are involved in their treatment plan they are more likely to reach their treatment goals. Bassman (1997) This involvement would include decision-making, setting rules and establishing routines.

As with other sections of this report, involvement in the decision-making could greatly enhance service users' response to treatment. These findings are confirmed by recent research Linhorst and Eckert (2003).

Recommendations

1) Service users should be fully involved in the planning of their drug treatment program.

2) The negative side effects of medication should be treated seriously and should be explained to the service user in detail.

3) Service users should be provided with choices regarding medication. Other forms of therapy should be explored instead of or in conjunction with medication.

4) Regular and timely review of medication with feedback from service user on benefits and side effects experienced thereby accepting the service user as knowledgeable on how medication affects him or herself.
Contact with Professionals

Introduction

It is generally accepted that the human face of medicine (that is the relationship with professionals) is as important as any medical intervention in mental health services. Effective communication is essential in order to establish a therapeutic relationship as well as 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

Main Doctor Contact

Sixty-two percent of the sample stated that a consultant psychiatrist is their main contact, while 15% said their main contact was the junior doctor.

Regularity of visits

We asked how often the service users see this doctor? From the results 38% saw the doctor at least once a month, while 21% saw the doctor once every three months.

Adequacy of contact

We enquired whether this contact with their doctor was adequate. A total of 76% of the sample found the number of times seeing their doctor was adequate. We further asked the sample the length of time they spent at a consultation. A total of 59% of the respondents visits to their doctor lasted 1-15 minutes while 29% of the sample visits to doctor lasted 20-30 minutes. Twelve percent of the sample stated that visits to doctor lasted 60 minutes.

Issues Discussed with Doctor

The main issues discussed were:

<table>
<thead>
<tr>
<th>Issue</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>47%</td>
</tr>
<tr>
<td>Concentration</td>
<td>9%</td>
</tr>
<tr>
<td>Sleep</td>
<td>20%</td>
</tr>
<tr>
<td>Well-being</td>
<td>9%</td>
</tr>
<tr>
<td>Appetite</td>
<td>20%</td>
</tr>
</tbody>
</table>

It can be seen from the table above that medication was the issue most often discussed at 47%. It should be noted that many of the sample stated they discussed a collection of these issues.

When asked were there issues the sample would like to have discussed but did not? Fifty-six percent stated no. Some comments on this topic were:

- The doctor gave me adequate time to talk
- I would like to discuss why I was forced into taking medication and also the reason why I was sectioned

A total of 20% of the comments reflected the need to discuss medication in greater depth.
Easy to discuss matters with the Doctor

We asked did the service users find it easy to discuss matters with their doctor. A total of 78% stated that it was.

Continuity of Doctor

When asked whether they saw the same doctor in the last 6 months, a total of 61% stated they had seen the same doctor. Of the remaining 38% who did not see same doctor we asked was the new doctor aware of their case history. 47% of these stated that they felt the doctors were not aware of their case history. We asked if the new doctor was not aware, how did this affect the service users? Some of the comments were as follows:

- I felt I was waiting for my main doctor to come back. The new doctor reduced my medication but I wasn’t that comfortable with it.
- I felt as if they did not care, when I was dealing with the new doctor.
- I had to explain everything again.
- Found it strange to see different doctors
- Didn’t affect me at all

Care and attention from professionals

The sample were asked were they satisfied with the care and attention received from the following professionals. Results are shown in table below:

<table>
<thead>
<tr>
<th>Satisfied with care and attention received from:</th>
<th>Yes</th>
<th>No</th>
<th>Moderately</th>
<th>No Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant</td>
<td>87%</td>
<td>9%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>Junior Doctor</td>
<td>63%</td>
<td>16%</td>
<td>3%</td>
<td>16%</td>
</tr>
<tr>
<td>Nurses</td>
<td>71%</td>
<td>3%</td>
<td>12%</td>
<td>12%</td>
</tr>
<tr>
<td>Community Nurse</td>
<td>73%</td>
<td>6%</td>
<td>3%</td>
<td>16%</td>
</tr>
<tr>
<td>Occupational Therapist.</td>
<td>34%</td>
<td>0%</td>
<td>7%</td>
<td>58%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>41%</td>
<td>3%</td>
<td>7%</td>
<td>48%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>33%</td>
<td>6%</td>
<td>3%</td>
<td>57%</td>
</tr>
<tr>
<td>Domestic Staff</td>
<td>70%</td>
<td>15%</td>
<td>9%</td>
<td>6%</td>
</tr>
</tbody>
</table>

From this table it can be seen that service users were satisfied the most with the care and attention received from their consultants. It should be noted that 57% had no contact with a psychologist; 48% had no contact with a social worker and 58% had no contact with an occupational therapist.
Discussion

This section clearly shows that service users have the highest regard for their professional carers. These results can be clearly seen in the table above, giving satisfaction ratings.

As doctors have the main responsibility for treatment, this section dealt mainly with service users' attitudes to their doctors. Service users are satisfied with their appointments with their doctors. 59% stated they did not have issues that they wanted to discuss with their doctor, other than what was discussed. It should be noted with regard to issues discussed with doctors, none of the service users commented on their involvement in treatment planning and only 9% discussed their wellbeing. Sixty-one percent saw the same doctor over the last 6 months. Those who did not see the same doctor had some concerns, however these comments could not be regarded as strong criticism.

The satisfaction rating service users reported with other professionals was very high. All comments received here were positive. These results are encouraging and we take heart of this high level of satisfaction.

However, with regard to multi-disciplinary teams, there seems to be a serious lack of some professional skills. The access of these multi-disciplinary teams should be reviewed for all service users. 58% of service users had no contact with an occupational therapist, 57% had no contact with the psychologist and a further 48% had no contact with the social worker. In Department of Health (1988) Stationary Office The Psychiatric Service ‘Planning for the future’ under the planning and evaluation section there is a clear mention that to ‘assign responsibility of psychiatric needs in each sector to a multidisciplinary team’ We wonder were these measures ever implemented as our findings show clearly the lack of such a team.

Recommendations

1) All service users, regardless of circumstances, must have equal access to a full multidisciplinary team as a matter of priority.

2) There should be broader issues discussed with doctors by service users. i.e. Well-being, social problems, employment and family etc.
Electroconvulsive Therapy
/E.C.T.

Introduction

This is a treatment offered to some service users as well as medication. It is given in order to lift depression and to interrupt thought patterns. ECT involves an electric current being passed through the brain. There is a good deal of anxiety and fear surrounding this treatment as its course of action is unclear and it has significant side effects. This section explores service users attitudes to E.C.T.

Main Findings

Use of E.C.T

Is this treatment used widely? We wanted to know from the sample how many were prescribed it. 44% of our sample were prescribed ECT.

Agreeable to have Treatment

After being prescribed the treatment we asked were the service users agreeable to taking this treatment? 94% of respondents were agreeable to have this treatment, although some did express personal concerns. One individual was so fearful of having E.C.T. that he escaped from the hospital.

- I absconded from hospital rather than having it
- I didn't mind
- I expected it to solve all my problems. I trusted the doctors
- I only felt the needle
- I was a bit frightened at the start, but I felt I could do anything to get well

Understanding of E.C.T and Side-effects

We asked did the service user have an understanding of E.C.T in terms of the treatment. forty three percent stated they did not understand the reason for having E.C.T. In terms of understanding the side effects of E.C.T., 50% stated they did not understand the side effects of this treatment. The following comments clearly shows the frustration of some service users with regard to the treatment:

- People should be given a lot more information about E.C.T.
- I felt bad about taking it
Benefits of E.C.T. treatment

Does the treatment work? We asked the respondents in their opinion did they get any benefit as a result of the treatment in the short and long term? The results were mixed with half not reporting any benefit for the short or long term. Some reported it worked in the short-term but its benefits did not last while others highlighted positive effects. Some felt strongly that it was harmful to them.

Did me good anyway
Looking back now, I feel that it had an awful effect on my brain
Made me better
It worked for me in the short-term but the effects didn't seem to last

Side effects of E.C.T. treatment

We asked the service users if they experienced any side effects. Forty three percent stated they experienced long-term side effects, 58% experiencing short-term side effects. Comments on side effects clearly show the diversity of views on help and harm with which service users perceive E.C.T. as a treatment.

- Severe headaches. Unbalanced and light headed
- Makes you lose your memory
- No- Not that much effect on me
- Memory loss
- Did me good I find
- Your memory goes
- A little memory loss but nothing major
- It causes long term depression
- Apart from headaches -no side effects

Use of E.C.T as a Treatment again

Seventy-one percent of respondents stated they would not use E.C.T. treatment again. Comments of some of the individuals that would not have it again include the following:

It's a barbaric form of treatment
I didn't find it good anyway
Refused to take it again
Discussion

Three audits were carried out for the Royal College of Psychiatry in Britain in the 1990's. Each has shown E.C.T. works in an unpredictable way, with random efficiency, and random damage. These audits admit that doctors do not know how it works, nor will they agree on how best to administer this treatment. Indeed the dose is decided by habit rather than by rational decree.

A large proportion of our sample did not know if they received any benefits yet many endured side effects: these results indicate the cost of E.C.T. to the service user may on many occasions outweigh the benefits of E.C.T. as a treatment. Many complained of headaches and/or memory loss. When considering, 94% of the respondents were agreeable to take E.C.T. after they were prescribed it, yet as 71% of these will never again use E.C.T. as a treatment, we have to the question it's benefits? It also suggests that alternatives to the use of E.C.T. should be explored.

Clearly service users need to be fully informed about this treatment before giving or refusing their consent. This should be included in a protocol for administering E.C.T. This informed choice and consent should give detailed knowledge of the unpredictability of the treatment. It should also tell the service user of the upsetting side effects. Many service users are frightened of it. This fact alone will upset the service users' perceptions of the treatment as a sensible alternative. There needs to be far more research and guidelines with the use of this treatment.

Recommendations

1) Service providers must give informed choice to service users and their families. This should be included in a protocol for administering E.C.T.

2) Service Providers should discuss alternatives to E.C.T with service users and their families.

3) As in the West Galway Pathway Report we recommend further research to explore and justify the reasons for using this controversial treatment.
Counselling

Introduction
In the absence of specific counselling therapies 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 to get a sense of service users' perceptions of counselling/talking therapy. Talking therapy can include cognitive behaviour therapy, counselling, group work and psychotherapy.

Main findings

Counselling/ Talking therapies attended
We asked our sample did they ever attend counselling or talking therapies? 70% of our sample stated they attended therapies provided by the mental health service.

The professionals who provided counselling/talking therapies
We asked the service users what professional provided this service?

<table>
<thead>
<tr>
<th>Professional</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>45%</td>
</tr>
<tr>
<td>Doctors</td>
<td>9%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>23%</td>
</tr>
<tr>
<td>Others</td>
<td>13%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>10%</td>
</tr>
</tbody>
</table>

From the table above it can be clearly seen that nurses provide the greatest proportion of counselling to service users.

Satisfaction with counselling/talking therapies
We then asked were the respondents satisfied with their counsellors. 72% of our sample stated they were satisfied with their counsellors while, a further 77% of the sample considered this therapy to be helpful. A total of 74% of respondents stated that they would attend this therapy again. Yet a further 47% of those interviewed said that they did not receive professional counselling after discharge from hospital and 95% stated that they were not at the time of the survey receiving counselling.

When we asked why did the respondents not avail of counselling after discharge some of the following comments were given:
- There isn't anyone in my area.
- I felt that I did not need it.
- I think that counselling is the most useful thing in the mental health service, but when I needed it the only person I could turn to was a priest.

One-to-one counselling
It should be noted here that all the above therapies were usually in a group setting. In this separate section we asked those persons who had one to one counselling, were they satisfied with their counsellor and did they find it helpful? Over half attended one to one counselling after discharge from hospital. A total of 82% of respondents who received this therapy were satisfied with the care and attention they received from their counsellors while a further 76% of those persons stated that it was helpful to them.
In general most of the comments on counselling/talking therapies were positive. Many of the respondents felt there should be a good deal more of this therapy.

- I could see no light at the end of the tunnel but after counselling I did.
- I could speak my mind and hear the views of other patients and the psychologist.
- It gave me the chance to talk to someone in confidence.
- There should be more of it.

Discussion

A total of 70% of those interviewed attended counselling or talking therapies. The comments show that service users' benefited from these therapies. There is currently one mental health counsellor working in the Tuam sector and one in the Portumna/Gort sector. 45% of the sample received their counselling from a nurse and only 23% from a qualified psychologist. Indeed, many service users only received group therapy that they considered as counselling. The East Galway Pathways team uphold the recommendation made in the report published by the Brosnan et al (2002) West Galway Pathways team in "The mental health service should contract or employ professionally trained counsellors/therapists as a matter of urgency" (Brosnan et Al). We feel that this should be given priority and consideration in the planning of the services for the future. In a recent study by Rethink (2003), when participants were asked to rate mental health care improvements, 49% rated talking therapies in their top three.

It is significant to note that only 5% of the sample were receiving counselling at the time of the survey. We wonder if the lack of this most sought after treatment is beyond the economic grasp of service users and should these treatments be available on medical card? Considering the high cost of the newer drug treatments surely counselling must be seen as a realistic alternative.

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 process, and how to access it within the mental health services, should be available to all service users.

3) Evaluation of counselling/talking therapy should be carried out on a regular basis.

4) There should be a concerted effort to provide an accredited community based post-discharge counselling service in East Galway, similar to addiction counselling services provided by the WHB.

5) Counselling should be available to service users through the general medical card system.
Activities in Hospital

Introduction
The activities department provides a variety of groups from Monday to Friday, which forms an integral part of in-patient treatment. Examples of activities available are: Relaxation therapy, Crosswords Cards, Quizzes. This section has been designed to explore service users experience of these activities, and assess how appropriate and useful these activities are in addressing the needs of the in-patients.

Main findings

Attendance at activities
Two-thirds of the sample attended activities in the Hospital. Over 80% of those wanted to attend activities.

Involvement in planning activities programme
We asked if the respondents were involved in the planning of their own activities. From the findings 56% of respondents were not involved in the planning of their own individual activities. Yet of those who were involved 83% of this sample stated they found their own involvement helpful.

Usefulness of activities
Are activities in hospital beneficial in any way to the service users recovery? Eighty percent of the sample found activities helpful in their recovery. A further 76% of respondents stated that they would like more choice of activities. Some of the comments are as follows:
- Rather than staying in bed - getting bedsores.
- Exercise is good for you.
- Awful tired exhausted.
- Kept me busy and occupied my mind

Activities attended
The following are the main activities that service users attended while in hospital: Crosswords, painting/drawing pictures, badminton, gardening, creative writing, bingo, quizzes, word wheel, playing cards, cookery, relaxation, walks, watching T.V., reading and chatting.
Activities most enjoyed/least enjoyed

From the comments the most popular activities were talking and meeting people with similar problems. Relaxation and taking therapy sessions were the next enjoyable.

Preferred Activities

When asked what other activities the service users would have preferred some of the suggestions were

- Music
- Walking and physical education

Weekend/Evenings activities

Previous studies have shown that weekend/evenings can be very lonely times for service users in hospital. We asked would the service users like activities extended to weekends/evenings? The results show that 68% of respondents stated they would like activities extended to weekends/evenings. Reasons given from their comments were:

- The weekends can be very long if you stay there. During the week you look forward to activities to kill the time.
- Yes, evening and weekends are boring.
- Weekends are long and lonely. By the time Monday comes around you head is full of bad thoughts again.

Physical Exercise

We asked did the service users receive any physical exercise while an in-patient. Forty percent of the sample stated they received no physical exercise while in hospital. Seventy six percent of respondents stated that physical exercise would have helped in their recovery.

Boredom in Hospital

A total of 65% of respondents stated that boredom was a problem in the hospital and in the alcohol unit. Here are some of the comments relating to boredom:

- The medication causes boredom.
- Sometimes it can be boring waiting for the group to start.
- I think that boredom is a serious problem in hospital because it makes people think too much about everything.

Day Trips

From the findings 84% of respondents felt that day trips from the hospital would be a good idea. Some comments of examples of these trips are as follows:

- Going on outings with a group of people.
- Damn trip out somewhere.
- Kylemore Abbey.
- It must be voluntary - Knock shrine.
Discussion

It is encouraging that of two-thirds that attended activities almost 80% of these wanted to go. This highlights the need for activities or occupational therapy in hospital. Great care must be taken that this practice does not reinforce a sense of helplessness and undermine the possible therapeutic value of activities because service users feel obliged to attend them. Whatever the rational for not involving all service users in the planning of their activities must be addressed, as so many respondents believed that this involvement in planning their programs would have been helpful to them.

From the results 80% of the sample found activities to be helpful in their recovery. This is a clear sign that activities are important to service users recovery and that service providers should encourage any possible promotion and development of this active recovery. Given that 76% of the sample wanted more choice in their activities programme, development of an individual activity programme is necessary. Sixty-five percent of respondents were bored in the hospital. From the comments, a huge number mentioned boredom to be a problem. Surely this is another example of the necessity to have interesting and stimulating activities within the restrictions of a hospital? Some sort of physical exercise must be introduced into the activity programme, as 40% of the sample received no physical exercise at all. Physical Exercise gives many benefits, relieves boredom, increases fitness and makes for a healthier mind. It combats weight gain, side effects of medication and isolation. One aspect of relieving boredom is day group trips into the local leisure centre that provide a range of physical activities. This could be done on evening and/or weekends, as boredom at these times is at it’s highest whilst an inpatient. As in West Galway (Brosnan et al) a gym should be made available to inpatients while in hospital.

Recommendations

1) Service users should be more involved in the planning of their activities.

2) There should be more choice available in the activities programme. These activities should be tailored to individual needs.

3) Service users should be able to attend activities of their choice without any undue pressure.

4) There should be more consultation between staff and service users regarding all aspects of their activity programme.

5) Activity programmes including physical exercise should be available at weekends and evenings.
Crisis in Hospital

Introduction

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

Main findings

We asked the survey participants had they experienced such a crisis outside routine hours? From the findings 23% of the sample experienced such a crisis after hours as an in-patient after hours. From these respondents we further asked, how long it took to see the duty doctor after hours in a crisis situation?

<table>
<thead>
<tr>
<th>40% of respondents</th>
<th>2 hrs</th>
<th>20% of respondents</th>
<th>10 hrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>20% of respondents</td>
<td>5 hrs</td>
<td>20% of respondents</td>
<td>12 hrs</td>
</tr>
</tbody>
</table>

From the table above it can be seen that 40% saw a doctor in two hours, yet 20% had to wait for twelve hours.

Here are comments on crisis satisfaction handling.

- Few minutes
- Sometimes I would see a doctor and sometimes the nurse refused to call the doctor
- 2 hours

Training nurses in Crisis Management

Respondents were asked should nurses be better trained in the handling of crisis situations in hospital? From the results 70% of respondents indicated that nurses should receive specific training in crisis response.

A number of respondents gave comments on the subject of crisis in hospital. Here are some of the comments:

- Tell the nurse
- The nurse can look after difficult patients in the hospital
- Patients should be allowed to voice their concerns more. Quicker actions are needed.
- Sometimes the professionals should learn from their mistakes
Discussion

Two to twelve hours is far too long to wait to see a duty doctor after hours in a crisis while in a hospital. A quicker response time is essential in order to prevent a worsening crisis. Whether there is an absolute need for this doctor or whether the situation requires the skills of a nurse should be decided by the senior nurse on duty. There would be a lesser need for a doctor to come if nurses were better trained to deal with crisis situations when they occurred.

Recommendations

1) There should be on-going crisis management training - this should be a priority of service providers.

2) Nurses should have more time to spend with service users experiencing a crisis
Preparation for Discharge

Introduction

Facing the 'real world' after spending a period in hospital can be a daunting prospect. Some service users may have to deal with work related problems, financial issues, social and family issues together with fear of relapse and the prevailing stigma that follows on from being in a mental institution. Thus preparation for discharge is vitally important in assisting the service users' transition from hospital back to the community. This section has been designed to explore users' experiences of preparation for discharge from the psychiatric hospital.

Main findings

Service users involvement in planning their own discharge

We asked would service users like to be involved in the planning of their own discharge? From the results 54% of respondents stated that they were not involved in planning their discharge. 81% of the sample reported that it is important to be involved in the planning of their discharge. Here are some comments on discharge planning:

- People should be discharged sooner and prepared better
- Good back up
- More counselling- less tablets
- I would advise people to take a break from hospital to get back to normality quicker.
- Back up from family/friends is very important then discharge and aftercare needed.
- There should be more contact with community nurses.
- I would like to be sure that I was looked after well.

Notice of Discharge

From the results 21% of respondents believed that the notice provided for them in terms of discharge date was inadequate.

Self-Discharge

Over a third (36%) of respondents revealed that they discharged themselves from the psychiatric hospital.

Fear of Discharge

We asked were the service users fearful of discharge. Sixty-four percent of respondents were not fearful of discharge.
Day/Weekend leave

How important is day and weekend leave to the service users' recovery while being discharged from hospital? Sixty-one percent of respondents stated that day/weekend leave was important to their recovery. It is interesting to note that 27% did not know whether it was important to their recovery.

Some comments on discharge were as follows:

- No. There should have been some counselling on a weekly basis after leaving hospital rather than a social worker.
- Just to take my medication that's what I was instructed to do.

Concerns and fears on discharge

We wanted to know what were the main concerns and fears of service users at the time of discharge. The following were the main areas of concern:

<table>
<thead>
<tr>
<th>Concern</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relapse</td>
<td>77%</td>
</tr>
<tr>
<td>Community attitude</td>
<td>46%</td>
</tr>
<tr>
<td>Financial concerns</td>
<td>61%</td>
</tr>
<tr>
<td>Employment</td>
<td>38%</td>
</tr>
<tr>
<td>Coping with everyday tasks</td>
<td>58%</td>
</tr>
<tr>
<td>Institutionalised</td>
<td>35%</td>
</tr>
<tr>
<td>Isolation</td>
<td>54%</td>
</tr>
<tr>
<td>Crisis Management</td>
<td>34%</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>50%</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>32%</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>50%</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>32%</td>
</tr>
</tbody>
</table>

The most frequently stated concerns are the fear of relapse 77%; financial concerns 61%; isolation 54% and living arrangements 50%.

Discussing concerns regarding discharge with professionals

How many service users actually discussed these worries with professionals? From the results 44% of respondents stated that they did not have the opportunity to discuss their worries about discharge with professionals.

Comments on discussing their worries to professionals were as follows:

- I find it hard to talk to them
- I was disappointed with the aftercare

However, when the service users did discuss their worries and concerns with professionals about their discharge, 86% of them found these talks helpful.

Levels of satisfaction with post-discharge care

Follow-up care and aftercare is necessary for most service users. From the results we found that 75% of the respondents reported that they were satisfied with their follow-up service.

Useful services on discharge

The respondents perceived that the following services would be useful if available in preparation for discharge.

- Information pack 77%
- Discharge Group 72%
- Advocate/Mediator 72%
- Support Group 46%

It can be seen from the table above that an information pack, discharge group, and an advocate are the main useful services on discharge.
Discussion

In the new disability bill before the Dail (Dr. Pillinger J. (2003) Disability Legislation Consultation Group Document for Equal Citizens) at the moment there is a section dealing with the importance of individual assessment of needs. This assessment can never be more relevant to service users' as when it comes to discharge from a psychiatric hospital. Given the life-long nature of mental illness service users' must be given the help they need to take the huge step back into the community.

Although 81% of respondents stated that being involved in planning their own discharge was important, only 25% were involved, with a further 54% having no involvement at all. Yet no one can protect them in the outside world or help them achieve their full potential. If service users are placed in a passive role with regard to discharge, does this not greatly increase their dependency on the services rather than facilitate the recovery process?

A staggering 35% discharged themselves from a psychiatric hospital. This figure compares unfavourably with the result from Brosnan et al West Galway (25%). These service users may leave before medical treatment is allowed to work. Would such a statistic occur in general hospital? We ask why is this? This finding clearly suggests that mental illness is still regarded by both service users and the general public as something to be ashamed of, something to be feared.

Every service user should be given adequate notice of discharge. The findings show that 21% were not given this notice. When service users have to go into the outside world many issues other than just medical must be addressed. Issues, such as accommodation, families, social security etc.

A further 64% of respondents were not fearful of discharge. This result is very encouraging. A large number of the respondents favoured an information pack, discharge group and mediator/advocate. They realise they need help with all the problems of facing life, home and the community while coping with mental illness.

Again a large number of people surveyed (75%) stated that they were satisfied with their follow-up care. This finding is welcomed. It shows that service users' wish to keep well/stay well and appreciate the great work of community staff that ensure they do. Of the small number of service users who discussed their discharge with professionals, 86% found these talks helpful. This is another welcomed result and shows

Recommendations

1) All service users should be actively involved in planning for their own discharge. This plan should not only address medication but also concerns and issues of service users on discharge (i.e. financial, social and vocational).

2) All service users should be given adequate notice of discharge.

3) The high rate of self-discharge should be investigated.

4) Useful services (i.e. information pack, discharge group and advocate) that the service users would like on discharge should be added to the already existing services.
Privacy

Introduction

It is likely that privacy may be of more importance to mental health service users than those using the general health services, given the particular nature of illness as well as the negative social attitudes, discrimination and stigma attached to this group. As such, the research team agreed that a separate section should be devoted to this issue. It has been designed to allow the sample to catalogue their relevant experiences and express their opinions on the level of privacy afforded to them by the East Galway Mental Health Service.

Main findings

Adequacy of Privacy

The respondents were asked if they found the levels of privacy adequate in four different sections of the mental health service? These sections were in hospital, in outpatients, in the alcohol unit and in supported accommodation.

<table>
<thead>
<tr>
<th>Adequacy of privacy</th>
<th>Yes</th>
<th>No</th>
<th>Moderately</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>In hospital</td>
<td>42%</td>
<td>32%</td>
<td>19%</td>
<td>7%</td>
</tr>
<tr>
<td>Out-patients</td>
<td>52%</td>
<td>21%</td>
<td>21%</td>
<td>5%</td>
</tr>
<tr>
<td>Alcohol unit</td>
<td>9%</td>
<td>27%</td>
<td>18%</td>
<td>45%</td>
</tr>
<tr>
<td>Supported Accommodation</td>
<td>33%</td>
<td>26%</td>
<td>13%</td>
<td>26%</td>
</tr>
</tbody>
</table>

It can be seen from the table above that respondent's perceived Outpatients section to have the highest rate of privacy. Here are a few comments on privacy:

- *Nurses and Doctors don’t respect their patients' privacy, as they should.*
- *I would like to see more space provided for each patient and more privacy.*
- *I strongly object to staff looking through my wardrobe and drawers. I feel like a prisoner some times.*

W.H.B. Accommodation

As can be seen from other sections (eg. Demographics) a large proportion of the individuals surveyed are living in Health Board supported accommodation. The rest of this section deals with these service users and the degree of privacy afforded to them in these hostels.
Treatment

From the results 29% of the sample were living in W.H.B. supported accommodation at the time of this survey. The type of accommodation is broken into three categories: 30% of these service users are living in high support accommodation; a further 10% are living in medium support accommodation; and 60% are living in low support accommodation.

Own room

A large percentage (90%) had their own bedroom but only half the respondents had a key to their bedroom door. Some of the comments on privacy are as follows:

- Everyone is entitled to his or her own bedroom and private affairs.
- I wouldn't like to stay in a rented house. I wouldn't like to stay in hospital. I'd prefer to stay at home.

Discussion

Of the comments given, three-quarters wished there was more privacy. This clearly shows the need to investigate service users' private space in the hospital and sheltered accommodation. The dignity of the service users is curtailed in these buildings. There has to be a clear policy on protecting individual private space. This should be clearly communicated to the service user at all times.

A total of 29% of the sample live in W.H.B. supported accommodation. Given the long term nature of this accommodation there is a need to respect service users' privacy. Complete strangers can be sleeping in close quarters with no relative near. One wonders why only 50% of this sample have their own bedroom key considering the fact that 70% of the sample were not in high support accommodation? It seems appropriate that service users not in high support hostels would have their own bedroom keys, thereby increasing their sense if privacy.

Recommendations

1) A Clear policy must be introduced to maintain service users' privacy. This must be communicated to the service users at all times

2) Every service user living in WHB accommodation should have the right to their own bedroom with their own key to the bedroom door unless clinical conditions suggest otherwise.
Community Care

* Crisis in the Community

* Day Care Centres

* Training Centres

* Transport
Community Care

Crisis in the Community

Introduction

This section investigates the critical experiences for service users in crisis in the community and the nature of response from medical and other professionals.

Main findings

Service users who had a crisis

Respondents were asked if they required help in a crisis situation outside the hospital? Half of those surveyed required help in a crisis situation outside the hospital. The following list is where service users went for help in a crisis situation. They were asked to pick one of the following:

<table>
<thead>
<tr>
<th>Facilitates Attended</th>
<th>Local Hospital</th>
<th>&amp; 73%</th>
<th>0%</th>
<th>27%</th>
<th>0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casualty</td>
<td>12%</td>
<td>25%</td>
<td>25%</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>Counsellor</td>
<td>18%</td>
<td>67%</td>
<td>0%</td>
<td>0%</td>
<td>33%</td>
</tr>
<tr>
<td>Friend</td>
<td>15%</td>
<td>80%</td>
<td>20%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Family</td>
<td>15%</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Samaritans</td>
<td>12%</td>
<td>25%</td>
<td>25%</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>Went to G.P.</td>
<td>18%</td>
<td>50%</td>
<td>0%</td>
<td>33%</td>
<td>17%</td>
</tr>
<tr>
<td>Priest</td>
<td>12%</td>
<td>50%</td>
<td>25%</td>
<td>0%</td>
<td>25%</td>
</tr>
<tr>
<td>Rape crisis centre</td>
<td>3%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Alcoholic Unit</td>
<td>9%</td>
<td>33%</td>
<td>0%</td>
<td>33%</td>
<td>33%</td>
</tr>
<tr>
<td>Gardai</td>
<td>12%</td>
<td>25%</td>
<td>50%</td>
<td>0%</td>
<td>25%</td>
</tr>
</tbody>
</table>

It should be noted that some service users picked more than one facility in a crisis situation. As seen from the table above, 33% of service users went to the admission unit of the psychiatric hospital in time of crisis and 18% visited their counsellor. The most helpful was family with the least helpful Gardai, Samaritans and casualty at 25%

G.P. care

We asked what did the G.P. care consist of for the service user in time of crisis? From the results 39% of the sample were given medication, 54% were referred on to other professionals and 9% were given crisis counselling.

Nurse's training

We asked if service users feel nurses need training in crisis management. A total of 53% of respondents agreed and 20% didn't know
Crisis in Hospital

The respondents who attended hospital were asked about their experiences there. A total 83% of respondents stated that the long waiting time at casualty only added to their distress. Half left without being seen by a professional and 66% of respondents stated that casualty was not a suitable place in a crisis.

Some comments on those who went to casualty are as follows:

- Very bad, not (efficient) enough.
- Staff were good and helpful.
- Most of the nurses were fine but you got the feeling they did not want you there unless you were very bad.

Discussion

Thirty three percent of the sample went for help to the admission unit in time of crisis. This shows that service users are still dependant on the psychiatric hospital for help when they might not necessarily need admission to hospital. Indeed it has been shown McClelland et al (1999) Mind Yourself Annual Report that the vast majority of help sought is simply a listening ear. Clearly there is a need to offer this type of crisis service in addition to services currently available. This perhaps suggests a need to expand the role of counselling in crisis. Other forms of help must be provided that would be of more benefit to the service user i.e. drop-in-centres, help lines and peer support. There was also an overall unhelpful response to service users when they asked for help from the Samaritans and Gardai. These groups may need training to assist service users in time of mental health crisis.

With regard to service users availing of Casualty 83% of respondents said that Casualty only added to their distress. This is almost identical to the figure for West Galway. Why are primary care treatments not used or known by service users? With only 8% going to their G.P.'s and a large percentage using voluntary groups, family or friends, there clearly does not seem to be any guidance as to a community based response to mental health crisis.

A significant proportion (18%) attended their GP, yet only half of those found this helpful. This study warrants further investigation. In a recent Rethink Study (Just one percent Jun '03) a third of respondents ranked extra GP training as top priority for improvement in mental health care (Just One Percent, p.6).

Recommendations

1) There should be an alternative to Casualty in times of crisis as there is clear evidence that attending casualty is unhelpful and distressing in some cases.

2) Other forms of primary care help should be available to service users in time of crisis.

3) The need for training for the Samaritans and Gardai should be investigated to help them assist service users.
Day Centres

Introduction

The role of the psychiatric day centre as defined by 'Planning for the Future' (1984) is to provide social care for patients whose needs cannot be met at community care day centres. The day centre may also offer treatment. Both day centres and training centres have a therapeutic role but unlike training centres the orientation of day centres is social. As a large number of this Pathways team are currently attending day or training centres we decided to look at both these services in East Galway. The role of day centres will become more important in the aftermath of the closure the local long-term psychiatric inpatient stay hospital although in recent times day centres have become more activity related.

Main findings

Attendance at day centres

We found that only 12% of the respondents did attend day centres.

How did these respondents find out about day centres?

The vast majority came to hear about day centres from staff of the mental health services. 67% of people heard from their psychiatrists and 25% from nurses.

Transport to day centre

We asked if transport was provided to the day centre, given the large geographical area. 50% of those interviewed were not provided with transport to the day centre.

The following table is a list of activities that the service users found helpful at day centres.

<table>
<thead>
<tr>
<th>Percentage of service users who found these activities helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact with staff</td>
</tr>
<tr>
<td>Learning new coping skills</td>
</tr>
<tr>
<td>Learning about illness</td>
</tr>
<tr>
<td>Develop new interest</td>
</tr>
<tr>
<td>Occupy time</td>
</tr>
<tr>
<td>Contact with other patients</td>
</tr>
<tr>
<td>Contact with other patients</td>
</tr>
</tbody>
</table>

Develop confidence 45%

Setting and achieving goals 54%

Learning to structure time 54%

Encouragement 64%
From the table it can be seen that helpful contact with staff is rated very highly at 100%. Developing confidence and setting goals are the activities that were found less helpful (45% and 54% respectively).

Involvement in planning activities

We asked if the service users were involved in the planning of their activities at the day centre. 80% stated that they had no involvement in the planning of their activities programme. We further asked if people thought that this involvement would have been helpful. 44% stated that they thought that it would have been helpful to be involved.

Boredom

We asked if boredom was problem in the day centre? 40% of the respondents found boredom to be a problem in day centres.

Care and attention of staff

We asked if the service users were satisfied with the care and attention they received from staff. Sixty percent of service users were satisfied, while 40% were moderately satisfied, with the care and attention they received.

Segregation of staff and service users

When asked if they had ever experienced segregation between staff and service users' in day centres, eg: separate tables, catering arrangements, toilets, 30% stated they had experienced it. Here are some of the comments service users made:

- Yes. O.K. I'm used to working with instruction.
- Yes. Cut off from staff

Discussion

Although only 12% of the sample attended a day centre, it is encouraging to note that the majority found attending a day centre helped them acquire new skills. This is a significant positive finding as the transition from hospital back into the community can be very difficult for many service users. Day centres can play a vital role at this stage, as they provide a stepping stone between hospital and home. The support of staff is available during the day and service users can be at home for the night.

It is shown that a substantial amount of service users were not involved in the planning of their activity programme. If service users are involved in planning their activities perhaps they will be more likely to be involved in these activities.

One positive outcome was that 60% of service users are satisfied with the care they receive from staff in day centres. 40% said they were moderately satisfied.

One worrying issue is that 30% had experienced segregation (e.g. separation at mealtimes, separate toilets, different quality food) at their day centres. This raises the question of the training provided to community staff. This may need to be altered in response to the recent recognition of Service Users as partners in care (Health Strategy 2001)
Day centres could play a vital role in aiding service users' to reintegrate into the community. There could be more instruction in social skills and basic life skills that service users' may have forgotten or have allowed to lapse during long stays in hospital. A variety of stimulating and appropriate activities to combat the boredom mentioned should be put in place, tailored to meet individual needs and regularly reviewed and adjusted.

Recommendations

1) Service users should be more involved in their planning of their own activities.

3) Training in basic life skills should be available to service users to give them practical help to re-adjust to normal life.

4) Day centres should be used to reintegrate service users back into the community through individual programmes based on identifying interests and skills and setting goals.
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 users vocationally.

Main findings

Attendance at training centres

Forty four percent of service users that attended training centres. Of the three training centres in East Galway our survey showed that 40% attended Ballinasloe, 47% Loughrea and 13% Toghermore.

When asked why service users attended training centres we received these comments:

- I needed to get out more
- I wanted to get trained and occupy time
- I wanted to get more skills, cooking, literacy/numeracy and social skills
- I wanted to meet different people
- I was referred by my doctor

Helped recovery

From the results 93% of trainees were not pressured to attend. In terms of length of time at training centres, 33% of trainees stated that they attended for the prescribed length of time with 67% of trainees stated that they attended for longer than required. We wanted to know if Training Centres actually helped service users in their recovery? 87% of trainees believed that the training centre helped in their recovery.

<table>
<thead>
<tr>
<th>% OF TRAINEES WHO FOUND THE FOLLOWING EXPERIENCES HELPFUL</th>
<th>Helpful</th>
<th>Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupying time</td>
<td>93%</td>
<td>Developing confidence</td>
</tr>
<tr>
<td>Contact with other patients</td>
<td>93%</td>
<td>Stimulating</td>
</tr>
<tr>
<td>(trainees)</td>
<td>93%</td>
<td>Learning to structure time</td>
</tr>
<tr>
<td>Developing new interest</td>
<td>93%</td>
<td>Learning new coping skills</td>
</tr>
<tr>
<td>Contact with staff</td>
<td>93%</td>
<td>Job seeking skills</td>
</tr>
<tr>
<td>Encouragement</td>
<td>93%</td>
<td>Learning about illness</td>
</tr>
</tbody>
</table>

From the table above trainees considered all of the issues mentioned helpful with learning about illness being the least helpful at 53% followed by job seeking skills at 64%.
Help with employment
We asked did the trainees obtain work experience? Sixty-seven percent of trainees stated they received work experience. We further enquired whether the trainees got a recognised certificate at the end of the course? Sixty percent of trainees stated they received such a certificate.

In terms of help with employment, attendance at training centres had a mixed impact

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>53%</td>
<td>Did not look for work they trained in.</td>
</tr>
<tr>
<td>33%</td>
<td>Went on to another course.</td>
</tr>
<tr>
<td>39%</td>
<td>Could not find work</td>
</tr>
<tr>
<td>25%</td>
<td>Were unable to work</td>
</tr>
</tbody>
</table>

A total of 53% did not look for work in the area they trained in for various reasons.

Training geared to returning to workforce
We asked was the training geared to helping trainees return to work? 40% of the service users felt that the training given to them at training centres was not geared towards their return to the workplace.

Care and attention of staff
We asked were the trainees satisfied with the care and attention they received from staff. 93% of the trainees stated they were satisfied with this care.

Segregation of staff and service users
We asked whether respondents had ever experienced segregation (e.g. separation at mealtimes, separate toilets, different quality food) between staff and service users at the training centre; 27% of trainees stated they did experience it.

- *I feel intimidated by this*
- *Small things such as using different delph for tea/coffee*

Training Allowance
From the results 53% of trainees stated the training allowance was not adequate.

Boredom in Training Centres
A total of 27% of trainees stated they were bored at the training centre with a further 27% stated that this boredom happened occasionally.

Discussion
Training centres were a highly emotive issue among the East Galway team as all were attending training centres or day centres at the time of the survey. Some have been at the training centres over 9 years and longer. Issues of whether they were actually training or in sheltered employment and simply doing occupational therapy were raised, as these fundamental differences were never clearly defined.

It should be noted that the training centres in the W.H.B. Region provide only Foundation courses for trainees. Do trainees need further basic training in these courses or do these courses qualify them for employment? This raises the question why the majority received a recognised certificate (60%), yet a massive 53% did not look for work in area they were trained. 40% of trainees felt that the training offered at these training centres was not geared to employment in the outside world.
Yet, when asked, 87% of trainees felt these training centres helped in their recovery. There were high percentages of activities, which trainees considered to be helpful. However these had little to do with gaining meaningful employment.

It is worrying to note that service users expectations did not alter much as a result of training. Occupying and structuring time, along with peer contact continued to be perceived as the most helpful aspects of training. The comments by trainees on why they attended the training centres mostly refer to the need of service users to keep their minds alert, keep occupied and not to be bored. When this has been achieved however, can training centres provide life skills that will improve the overall well being of service users?

These life skills should be an inherent part of the training centres' curriculum yet should never be seen as hobbies or treated lightly. Some training centres in the East Galway area have developed this curriculum to an excellent degree. We hope others will follow.

Sixty-six percent of trainees gained work experience. This is encouraging as it suggests a commitment of the training centres to give trainees experience of work. It is essential that local employers liaise with training centres and service users to achieve the expected level needed to obtain work in the current job market. This would also include partnership links with recognised training agencies to ensure the marketability of qualifications and training.

These findings highlight the need for a provision of individual assessment of need. Standards and gearing trainees towards employment must suit the trainee at all times yet must be flexible to adapt to the abilities of each trainee. If employment is one of the basic goals of recovery at these training centres why is it that 64% of the surveyed sample is long-term unemployed?

The fact that a high proportion (93%) of service users were satisfied with staff is encouraging. This finding shows service users given the right environment will respond positively to learning and developing new skills. It also shows staff in a favourable light with service users appreciating their commitment and teaching skills.

Service user groups are being developed in partnership with staff in these training centres. This effects a positive mind set and change has been agreed, not imposed.

**Recommendations**

1) **Review the role and purpose of training centres and their effectiveness in assisting service users vocationally through service users evaluations.**

2) **Training centres should liaise with local companies to find what the expected level of training that is needed to obtain work in the current job markets?**

3) **Develop links with recognised agencies and employers to ensure the marketability of qualifications**

4) **Provide work experience as an essential part of training for all.**

5) **There should be greater autonomy within the centre to provide training at a variety of levels appropriate to needs. This will allow trainees of varying levels of ability to participate and to move onto employment directly.**

6) **Social activities and outlets are provided in some centres and these should be developed in all centres.**
Transport to Day Centres and Training Centres

Introduction

Because of the rural nature of East Galway, we decided to add this section to the questionnaire. People in general have to travel some distance to use day centres and training centres. We needed to know if transport was provided to these services and if it was free of charge and reliable.

Main findings

Transport provided

We asked whether transport was provided to take the service user to and from the training/day centre. A large percentage of respondents (80%) who attended either day centres or training centres were provided with transport. Of those who use the transport facilities, 100% found the transport provided to be reliable.

Pick up/Drop off points

We wanted to know how far the service users had to go in order to get to the pick up point?

- A quarter of a mile 73%
- A mile 9%
- A half a mile 9%
- 1-2 miles 9%

As can be seen from the table above the majority of service users have to travel a quarter of a mile or less before their pick up point.

Adequate and happy with transport

The sample was asked if they found this service adequate? 91% of respondents stated they found the service adequate. A further 91% of our sample was happy with the transport provided with a 100% of our sample stating that there was no charge for this service.

Taxis

We asked did the service users need a taxi to and from these premise? Eighteen percent stated they needed to use a taxi service. A total of 67% of these respondents stated there was a charge.

Discussion

Over the past 20 years people with mental health disabilities enjoy greater transport movement. Most public transport is free to them. This has greatly increased their independence and enabled them to contribute to their own welfare and that of the community. Also at these day centres and training centres there is usually a Centre Bus that not only collects service users from their homes but also takes them on local trip i.e. swimming pool, football training and outings. The service users’ are happy with the transport provided to day centres and training centres.
Aftercare

* Employment

* Well-being

* Housing
Employment

Introduction

Employment is a key element of social inclusion. It builds confidence, generates feelings of self worth and structures the day. It provides financial returns and aids personal development. This section was included to explore the impact of mental health difficulties for service users on employment issues.

Main findings

Long-term unemployment

We asked were the respondents long-term unemployed? Almost two-thirds (64%) of the sample stated that they were long-term unemployed. However, 91% stated work was important to them.

Mental health and employment

Mental health had a considerable impact on employment with three quarters (76%) stating that their illness had prevented them reaching their full potential in the workplace. A further 69% of respondents stated that they were too ill to work at some time during their illness.

Returning to work

A total of 65% of respondents were in full time employment before experiencing mental health difficulties. None of these individuals returned to their previous type of work, with 44% changing to part-time work after their illness.

Stigma and employment

Among service users, disclosure of their mental health difficulties to the employers is a major obstacle. We asked respondents did they inform their employers of these difficulties? Half of respondents stated that they did not inform their employer (not sheltered) of their mental health difficulties. We further asked when the employers did know about their mental health difficulties, was there discrimination against the service user? A quarter stated that employers discriminated against them.

Help in returning to work.

We asked the sample did they receive any help in returning to the workplace? Given that service users particularly lack confidence, and skills, (see Well-being, Demographics and Training centres sections) we wanted to know if there is any direct help for them to return to the workplace; Seventy-four percent of the sample stated they did not get any help in returning to the workplace. The following represents the main people who helped service users back to work:

Friends 27%  Other patients 6%  Social Worker 21%  Back to work group 3%

This shows over a quarter of the service users relied on friends to get them back to work.
Service users stated whether they found the following agencies useful in returning to work:

- W.H.B. 45% Useful
- Fas 32% Useful
- Rehab 20% Useful
- Training Courses 33% Useful

It can be seen that less than half found these agencies useful, with the most useful being the W.H.B. services (45% found them useful).

Service users were further asked to list useful support systems that would help them back to work.

- Contacts list 90% Useful
- Community Employment schemes 76% Useful
- Information pack 74% Useful
- Sheltered Employment 67% Useful
- Person assigned 32% Useful

In terms of supports that would help people go back to work, it can be seen that all supports listed with the exception of a person assigned to an individual were found to be useful by the majority of respondents.

**Discussion**

Everyone's basic human right is to have access to work, because it provides the means to support yourself. A job is the first step out of poverty. A job is the key to creating wealth and distributing it equitably. According to the World Health Organisation (2001), work is important to positive mental health. It is at the very core of contemporary life for most people, providing financial security and allowing the individual to make a meaningful contribution to community life.

Yet with only 21% of people surveyed in full-time employment and 21% in part-time employment, we ask is there anything tangible being done to solve this problem? 90% of the survey stated that employment was very important to them, yet 64% perceive themselves as long-term unemployed. This problem is not going away easily! Not only does employment give financial rewards, it can lift people out of the poverty trap, and more importantly give a sense of worth. It also promotes recovery, combats isolation, prevents relapse and provides structure and a sense of worth to one's life.

With regard to help in returning to the workforce, 76% of our survey stated that they got little or no help from any agencies. Existing government schemes for helping people back to work (e.g. Employment Support Scheme, Employers Retention Grant, Disability Awareness Training for Employers Grant etc.) do not appear to have helped these service users included in the study.

If full-time employment is the government's goal for all of its citizens, we ask are they really taking one of the most marginalised groups in our society seriously? Information about back to work schemes should be made available to mental health service users. Agencies and services should also be more pro-active in helping mental health service users obtain jobs. This should include considering alternative options such as supportive employment, sheltered workshops, or occupational therapy. In addition, training should be provided to service users to facilitate their return to the workforce. On the job support could include personal development and/or stress management procedures.

Half of the employed people surveyed said that they did not inform their employer of their mental health difficulties. It seems that the stigma of mental illness is alive and well in Ireland today. People must be given real help to deal with mental health difficulties. The stigma of mental illness seemed to be a major barrier in returning back to the work place.
Recommendations

1) Information about back to work schemes should be made available to mental health service users.

2) The providers of all agencies and services should broaden their scope and be pro-active in obtaining jobs for mental health service users. Consideration should be given to other alternative employment options (e.g. supportive employment).

3) Service users must obtain essential training to facilitate their return to the workforce.

4) Multi-agency programmes should be implemented, based on best practice to help reduce the discrimination and stigma associated with mental illness in the workplace.

5) More flexible structures should be in place to support people who want to avail of the opportunity to go back to work. At the heart of these structures is a person centred approach meeting every service users individual needs.
Well-being, Social Interaction and Coping Skills

Introduction

Well-being is regarded by this research team as one of the most important sections of this entire report. It acknowledges that service users are more than the sum total of their problems and treatment. This section explores the myriad of ways service users' have learned to cope with and recover from mental health difficulties.

Main findings

Involvement with organisations and self-help groups

We asked the respondents if they were involved in mental health groups and organisations. The following list shows this involvement.

<table>
<thead>
<tr>
<th>Alcoholic Anonymous</th>
<th>Samaritans</th>
<th>Aware</th>
<th>Other Voluntary Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>32%</td>
<td>18%</td>
<td>21%</td>
<td>24%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sports Groups</th>
<th>Religious Groups</th>
<th>Social &amp; Political</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>30%</td>
<td>18%</td>
<td>9%</td>
<td>27%</td>
</tr>
</tbody>
</table>

It can be seen from the table above that the greatest proportion of service users were involved in Alcoholic Anonymous and Sports Groups.

Positive coping strategies

Respondents were given a list of coping strategies (both positive and negative) and asked to state which ones they had used.

<table>
<thead>
<tr>
<th>Talking to Friends</th>
<th>Listening to music</th>
<th>Reading</th>
<th>Watching TV/Video</th>
</tr>
</thead>
<tbody>
<tr>
<td>95%</td>
<td>85%</td>
<td>85%</td>
<td>71%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exercise</th>
<th>Healthy Diet</th>
<th>Gardening</th>
<th>Dancing</th>
</tr>
</thead>
<tbody>
<tr>
<td>65%</td>
<td>65%</td>
<td>41%</td>
<td>35%</td>
</tr>
</tbody>
</table>

The table above clearly shows that talking to friends was the most frequently stated coping strategy at 95% followed by listening to music and reading, both at 85%.

The following are some of the comments that service users perceived to have positive effect on them:

- Gym and Swimming pool. I enjoy and it is great exercise and you come out refreshed.
- Listening to music, walking and swimming.
- Keeping fit used to help
- Get out in the air, meeting people and going out at weekends
Aftercare

Negative coping strategies

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking</td>
<td>50%</td>
</tr>
<tr>
<td>Illegal Drugs</td>
<td>3%</td>
</tr>
<tr>
<td>Under/Over Eating</td>
<td>36%</td>
</tr>
<tr>
<td>Gambling</td>
<td>9%</td>
</tr>
<tr>
<td>Drinking</td>
<td>27%</td>
</tr>
</tbody>
</table>

The table above shows that smoking was the most frequently stated negative coping strategy. 50% of respondents smoked.

Alternative or complimentary therapy

Some service users reported using Alternative or Complimentary Therapies. The list below emerged from our findings:

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relaxation Therapy</td>
<td>38%</td>
</tr>
<tr>
<td>Meditation</td>
<td>35%</td>
</tr>
<tr>
<td>Massage</td>
<td>19%</td>
</tr>
<tr>
<td>Herbal Remedies</td>
<td>15%</td>
</tr>
<tr>
<td>Homeopathy</td>
<td>15%</td>
</tr>
<tr>
<td>Aromatherapy</td>
<td>12%</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>6%</td>
</tr>
<tr>
<td>Tai Chi</td>
<td>3%</td>
</tr>
</tbody>
</table>

This table shows that service users prefer relaxation therapy and meditation as the most frequently stated alternative therapies.

Drop-in-centres

Drop-in-centres are fast becoming one of the ways in which service users can learn to cope with the outside world. They are being introduced in some parts of Ireland. We asked the service user would they use such a Drop-in-centre run by service users. 44% of the sample stated that they would use such a Drop-in-centre.

Feelings about mental health difficulties

1) Guilty
We asked did the sample feel guilty about their mental health and 27% reported that they felt guilty about their condition.

2) Confidence and self-esteem
Over three-quarters of service users (77%) reported that their mental health problems had a negative impact on their confidence and self-esteem.

3) Isolation
Isolation is a serious problem with service users: as is shown in the Demographic section a huge percentage of service users are single. This worry is increased with the fact that this sample is of an older generation. Almost two-thirds (62%) reported that their illness made them feel isolated. Comments on isolation are as follows:
- Isolation from the friends I used to have
- I would like people to be more honest and direct about their illness.

4) Social exclusion
We wanted to know how the service users felt on being socially excluded. Half of the respondents (53%) reported that they felt socially excluded. Among the comments in this section dealt with stigma. Here are some of these comments on stigma:
Aftercare

- There is an awful stigma on mental health
- The stigma of mental illness is still a very big problem.
- It is a pity there is still stigma - people don’t talk about it - they push it aside - if it was open, it - would be easier on everyone
- I think there is a stigma attached to mental illness.

5) Alternative Therapies
Due to the low income of most service users, we wanted to know if they would use alternative therapies for their mental health if they were available on a medical card. Seventy-one percent reported they would use alternative complimentary therapies if they were available on the medical card. Comments on alternative therapies were as follows:
- ....I feel that alternative health approaches are very useful.

Discussion
The findings in this section reveal the unique and personal way that participants are coping with their lives. These coping strategies covered a broad spectrum and include groups, hobbies, individual techniques and complimentary therapies. It is evident that there is a low uptake of self-help groups among the survey. We wonder if information about such groups is reaching the service users. It is interesting to note that the highest coping strategy among service users is talking to friends (94%). This finding clearly shows service users need people to interact with socially. Social contact is an important part of recovery and a protective factor in mental health.

In the negative coping strategies smoking was the most frequently stated at (50%). This figure is far higher than the general public’s percentage at 27% Fiel et al.(2002) Slan report. What can be done to help service users to have a healthier lifestyle given the many alternatives that are now available to help them stop smoking? These findings suggest that there may be a need for the W.H.B./Health Promotion Department to work with service users to help reduce the percentage of service users smoking.

Service users would like to have a drop-in-centre in their area. This is a new concept whereby service users themselves can meet and communicate with other service users. Cruinniú drop-in-centre has already started in Galway City. It’s the first of its kind in the West where service users support themselves. There are plans in operation to have two such new centres in East Galway namely in the towns of Loughrea and Ballinasloe. The findings provide support for the development of this service. It would help reduce the isolation many service users experience after their illness, and help build on the positive coping strategies they currently use.

Complimentary Alternative therapies were strongly supported. Seven-one percent of sample would use them if they were on the medical card. However these therapies would be ‘out of the reach’ financially for most service users as they are not covered by the medical card scheme. Existing mental health services should facilitate the use of alternative therapies for service users. Service providers should be obliged to help in this area. If the Service providers are serious in their claim to have a holistic approach to mental illness then existing mental health services should facilitate the use of alternative therapies e.g. relaxation therapy, meditation by service users.
With regard to their personal feelings about mental health, a high percentage felt guilty, isolated and socially excluded. Stigma is still a worrying aspect for service users. Although the walls of the mental health institutions are long gone, the general public's negative attitudes remain. If the service providers see mental health in the future as community based health care then surely they must be pro-active in educating the general public in combating fear, ignorance and bias towards service users.

Recommendations

1) Information about self-help groups and other support organisations should be available through the W.H.B. This information should be constantly updated.

2) Service providers should develop a holistic approach into all aspects of service users health. Not to treat mental health difficulties as separate but as a part of service users emotional, physical, social and spiritual health.

3) Alternative and complimentary therapies should be available to those service users on low incomes.

4) Service providers must make a concerted and imaginative effort to combat the stigma of people with mental health difficulties. Alternative methods have to be found to remove barriers of stigma and isolation.

5) Consideration should be given to develop a role for the Health Promotion Department to assist with service users to help reduce the proportion of service users smoking.
**Housing**

**Introduction**

Adequate housing and homelessness were issues for the research team as most had known a service user who was homeless at some time during their illness and when leaving the hospital. The fear of not having one's own home was identified as a common experience among users of the mental health services.

**Main findings**

**Being homeless**

We asked the respondents have they ever been homeless since they became involved with the mental health services? It should be noted that all enumerators were required to give a broad definition of homeless to each person surveyed as follows:

*Homelessness includes not having your own place, inadequate accommodation or sleeping in a friend's place as well as sleeping rough.*

From the results, 12% of the sample reported homelessness since using the mental health service.

**Loss of accommodation**

A quarter (25%) lost accommodation through illness. The reasons for these were:

Twenty five percent stated that they had lost their accommodation due to the stigma of mental illness and a further 75% named financial reasons for losing their accommodation. We wondered what effect the lack of suitable accommodation would have on illness? Sixty-nine percent stated that lack of suitable accommodation could exacerbate their illness.

**Current accommodation**

We asked the respondents were they now in suitable accommodation; Ninety-one percent stated that they had suitable accommodation at present, of these 29% have their own home. Fifteen percent were in private rented accommodation and 12% were living in their family home, 29% were in W.H.B sheltered houses.

**Council housing**

Only 3% were living in council housing yet 27% were on the council-housing list. Of these 75% were on the waiting list for more than one year with a further 25% on this list for more than five years.

**Comments on housing** were as follows:

- It is a big issue for some - a lot of people don't have a home when they come out of hospital and maybe no job, which is twice as bad, which could make them ill again. Good quality housing should be available - people entitled to it as a member of the community.
- Too expensive
- I think that it is really important for people to have proper housing
- I am waiting on a house for the last five and a half years
Discussion

Homelessness was defined for the purposes of our study as not having your own home, sleeping at a friend's home, as well as sleeping rough or staying in a hostel. At the time of our survey as in West Galway, none of our respondents were homeless, because in order for us to contact them they had to have an address. But 12% of them reported at least one episode of homelessness since they started using the mental health services. This compares unfavourably with a national average of less than 1% and clearly shows that people with mental health problems encounter the threat 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 (Holmquist 92002). Indeed 58% of a homeless study Hourigan and Evans (2003) reported having mental health problems or illness compared to one percent for the general population Evans and Jones (2001).

The finding that only 3% were living in council housing is a shockingly small figure compared to the large number of 71% who were in receipt of social welfare. This means that many people with mental health problems are dependent on rentals in the private sector, which because of poor tenancy laws is very insecure. Also, those living in the family home can experience insecurities in relation to accommodation needs when elderly parents die and the family home is sold. The availability of council housing was a big issue for some of our respondents who felt that these should be available as a priority to people with mental health problems as well as people with physical disabilities.

The National Economic and Social Forum (2002) recommended 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 collection of responses from independent housing, sheltered housing through to institutional care. To the best of our knowledge none of the recommendations made have since been addressed.

Three-quarters (75%) of those surveyed had lost accommodation for financial reasons. Over two-thirds (69%) of the sample felt that their illness had been exacerbated by lack of adequate accommodation and 25% had lost accommodation due to the stigma, which is still attached to mental illness. The findings above demonstrate the impact that accommodation can have on mental health. This could also affect recovery prospects or staying well for service users' and may be playing a role in the "revolving door syndrome". These findings would also suggest that providing housing for people with mental health difficulties should be a Government priority. Maintaining the current accommodation while a person is in hospital is also of the utmost importance.
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. We would like to see a partnership developing between the W.H.B. and the county council to ensure that service users accommodation will be treated as a priority.

With the impending closure of St. Bridgid's Hospital Ballinasloe, this raises the question of the impact on the housing situation within the different local communities concerned. Will this bring added difficulties for service users? Will it create more problems of stigma and isolation and N.I.M.B.Y.ism (not in my backyard) or further segregation for service users to cope with?

**Recommendations**

1) A percentage of local authority housing stock should be set-aside for people with disabilities, including mental health service users as recommended in the West Pathways report.

2) The W.H.B., the county council and voluntary agencies should work in partnership to help address the accommodation needs of mental health service users.

3) Maintaining current accommodation while a person is in hospital should be of the utmost importance. Social welfare officers should make sure accommodation is secure.

4) The provision of a specialised mental health service and supported housing for homeless people with mental illness should respond to local need in this region. The provision of a mental health social worker and community mental health nursing service for homeless people should be a priority. Hourigan and Evans (2003)
Final Discussion

Introduction

The study was aimed at empowering service users and assisting service providers in planning for mental health services in the future. A questionnaire designed by service users was the basis of this study. This involved one to one interviews with 34 mental health service users that averaged between 1-1.5 hours to complete. The keys issues which arose in the results are discussed in this section.

Overcoming the barriers

The East Galway team feel empowerment starts as a learning process. When we first met, we were very cautious and wary of one another. There were no counselling sessions during the entire process whereby conflicts in the group could be dealt with. Coupled with these difficulties the distances travelled and lack of transport added greatly to delays. Also the poor facilities (we never had a base to work from as our venues changed from week to week) did not help. Indeed, a computer only became available at group meetings towards the end of the research.

As a result, it took months for the group to trust one another and lasting friendships to form. As the goals were met, respect and great understanding of each other developed within the group. We were now one group all aiming for one goal. One of the main empowering achievements was that the entire group acquired a better understanding of themselves and other service users.

Practical Outcomes

The project has contributed to a number of very tangible and practical outcomes:

1) A new mental health Drop-in-Centre for service users run by service users is being set up in the town of Loughrea. A committee has been formed and a premises has been already leased. There are plans to set up another centre in the town of Ballinasloe. We wish them well in the future.

2) East Galway Pathway's service users have been involved in many sub-committees of the Future Shape Steering Committee in the East Galway Area. These committees were set up in order to strengthen community care policy into the area and to close down the local longterm psychiatric hospital in the area.

3) The East Galway team had involvement in the W.H.B. mental health strategy consultation event in Galway late last year.

4) Because of the many information days, the East Galway team are now able to speak in public. This has given us great confidence.

5) The personal stories at the start of this report highlight the positive influence that the project has had on participants in the study. It has helped individuals and facilitated their ongoing recovery.
Response rate

Only 34 service users were surveyed out of a total of four hundred who were asked to give their consent to take part in study. It must be remembered that there was no reminders sent. This was a very poor response rate of 8.5%. Coupled with this, the many information days that the team gave around east Galway should have increased this figure. Why is this? In relation to the interviews, the East Galway Team felt that service users were apathetic and indifferent to the survey. There appeared to be a belief that this survey was not going to change anything. The East Galway team also felt that stigma, fear of going public about their illness made many service users shy away from taking part in the survey. Whilst the study cannot claim to represent the views of all service users, the 34 interviews that were undertaken provide an in-depth insight into the experience of users of mental health services in East Galway, and will facilitate the planning of mental health services in the future.

Information

One of the recurring results throughout the entire report is the absence of information. From first contact section, preparation for discharge to aftercare, service users and their families need to obtain this information to deal with the possible lifelong nature of the service users mental health difficulties. Service users are not receiving this information. There are many reasons for this. Staff may be overworked and cannot afford the time to give information, staff maybe too specialised and do not have information on other topics. In addition, service users may be too ill to assess this information. Also the lack of a central information service may debilitate service users. This reinforces the need for a multifaceted approach with all agencies working together to respond to the need of mental health service users. Families of service users are also not being given the appropriate information as this study clearly shows. A recent conference launched a research initiative called ‘The Informed Patient’. According to Mr Ivor Callely T.D., the report makes clear that a focus on informing the service user as a participant could be a new source of energy within the health system. Mr Callely states that “In our health system patients are the most significant actors and are also the most significant resource. Their information needs and their information input have not in the past received sufficient recognition”.

Professional Therapeutic

Service users overall were very happy with the care received from the health professionals, a finding which somewhat contrasts with the research report in West Galway particularly with regard to doctors. Whilst the finding is promising there is evidence throughout this report that more communication, dialogue, and understanding between service users and professionals is needed.

Medication

This section of the report we feel needs a separate final comment. If medication is not dealt with carefully and collaboratively from First contact to Aftercare the problem of non compliance will occur. It is imperative that service users be given all the time and space necessary to enquire about their medication. Further that information be freely given and explained. When you consider that every service user in the sample was prescribed drugs and the vast majority are self administering these drugs the doctor should give the utmost respect to the service user. Remember the service user has to contend with all the side effects and some service users are very dubious as to whether these drugs actually work or not. There should also be other recovery treatment available in conjunction with medication.
Medication should not be regarded as a 'cure all' or a 'quick-fix' remedy. A study by the Irish Patient's Association indicates that people receive information on their medication from either their doctor or pharmacist. It has emerged that just over half of the GPs surveyed told their patients of the potential side effects of their medication.

Balance of Power

Over the past year there has been some power shift to service users from the service providers. There is a service user on the Mental Health Strategy Group of the W.H.B.. Service users were invited to consultation meetings of this strategy group. This East Galway Pathways project together with the West Pathways clearly shows a shift in thinking. Whilst such initiatives from the service providers are welcomed, there is a need to see many more tangible results in order to get a genuine commitment to empowerment from the service providers. This should be considered when developing the new mental health strategy for the W.H.B..

Recovery

There are many documented definitions of recovery models Turner-Crowson and Wallcraft (2002), Montgomery County Recovery Task Force (1997), Thompson (1997). However these models mainly deal with the service user's own personal individuality. The East Galway Team feel it is essential that a broader attitude to recovery be adopted. The service user is part of a community. They must have the important abilities to share care and be fair to other members of this community. As the Grow self help organisation literature states 'You alone can do it, but you cannot do it alone'. The East Galway Pathways team learned this reliance on other members of the group the hard way.

Conclusion: The Way Forward

Pathways vision of building on energetic and innovative ways to engage with staff, management, voluntary agencies and the community in order to continue empowering the service users and staff to make positive changes for the benefit of all. This will lead to improved mental health for the entire community.
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