



contents

Foreword by Minister	2
Message from Chair	3
Acknowledgements	4
Background	5
Section 1 – Personal Demographics	9
Section 2 – Admittance Procedures	13
Section 3 – Service Satisfaction	14
Section 4 – Complaints and Complaint Procedures	19
Section 5 – Information	21
Section 6 – Choice	23
Section 7 – Environment	26
Section 8 – General	27
Conclusion	36
Appendix 1	37
Appendix 2	43

Foreword by Minister



In preparation for the new national policy framework for the development of mental health services, the members of the Expert Group on Mental Health Policy recognised that there existed a group of people who, for one reason or another, would be unlikely to engage in the broader consultation process. The Irish Advocacy Network was therefore commissioned to undertake a comprehensive one-to-one consultation process with service users in the Adult Mental Health Services. This Report What we Heard is the result of that process.

The responses of those who participated are based on subjective experiences. The issues arising are not new; lack of choice, lack of information relating to rights and treatment are common themes throughout the report. Issues of poverty, not having meaningful occupation or housing and feeling isolated as a result of mental ill health reiterate the stigma associated with mental illness. Over reliance on medication and lack of access to alternative treatments are also highlighted.

This report will facilitate further discussion on advocacy services and their role in the overall development of services for people with mental illness. I believe it will also have a significant impact on the work of the Expert Group in the development of a policy framework for mental health.

A handwritten signature in black ink that reads "Tim O'Malley". The signature is written in a cursive, flowing style.

Tim O'Malley T.D.,
Minister for State at the Department of Health and Children

Message from the Chair of the Expert Group



I am delighted to present this Report – *What We Heard* – which, along with *Speaking Your Mind*, represents the first results of the work of the Expert Group on Mental Health Policy.

The Expert Group has been charged with the responsibility of preparing a national policy framework for the development of mental health services. The work of the Expert Group is informed by the wide body of knowledge and varied perspectives brought by a diverse membership including a range of professions, voluntary bodies, service providers and service users.

One of the first, and most crucial, steps of the Expert Group was to initiate an intensive consultation process – involving written submissions, questionnaires and consultation days – that would give us a genuine understanding of present service provision and provide us with signposts for the services to be delivered in the future.

This Report – *What We Heard* – represents the voice of the users of the services. The Report provides a compelling picture of users' experiences of current service provision; a picture that has its positive elements but that also challenges us to face the existing gaps and shortcomings and bring the mental health services into something new.

The feedback given to the Expert Group establishes a foundation on which we can base a policy framework that has substance and that can bring service provision to higher levels of effectiveness and greater user satisfaction.

The Expert Group's acknowledgement of the power of user feedback reflects the new climate in service-provision in which the user is at the centre. The commitment of the Expert Group is to keep the user as the central focus in the development of the new policy framework.

A handwritten signature in blue ink that reads "Joyce O'Connor". The signature is written in a cursive, flowing style.

Professor Joyce O'Connor
Chair

Acknowledgements

Paddy Mc Gowan, CEO, Irish Advocacy Network.
John Redican, Management Committee, Irish Advocacy Network.
Collette Nolan, Director of Development, Irish Advocacy Network.
Karen Taylor, Director of Advocacy, Irish Advocacy Network.
Noreen Fitzgibbon, Area Coordinator, Irish Advocacy Network.
Margaret O'Connor, Area Coordinator, Irish Advocacy Network.
Brian Hartnett, Regional Advocate, Irish Advocacy Network.
Patrick Murphy, Regional Advocate, Irish Advocacy Network.
Breda Prunty, General Manager, Irish Advocacy Network.
Orla Treanor, Administrator, Irish Advocacy Network.
Dr. Fiona Keogh, Research Psychologist
Bairbre Nic Aongusa, Dept of Health and Children.
Marie Cuddy, Department of Health and Children.

About the Irish Advocacy Network (IAN)

The Irish Advocacy Network (www.irishadvocacynetwork.com) exists to promote and facilitate Peer Advocacy on an island-wide basis. This is achieved through the provision of Information and Support for Mental Health service Users and/or Survivors. We aim to support people in speaking up for themselves and in achieving empowerment by taking control of their own lives. The Network is made up of a management committee, staff and volunteers.

The Irish Advocacy Network (IAN) was formed from the first user run user led conference in Derry in November of 1999, a three day conference that was organized by Mind Yourself Derry an Associated Group of the Irish Advocacy Network. The conference, themed "VOICES", gave service users a collective voice for the first time and the Irish Advocacy Network was formed.

IAN works within a broad range of mental health service provision contexts and has carried out a number of service audits for various Health Boards in the Irish Republic to assess current service provision satisfaction, treatment models and methodologies and the systemic barriers to well being and recovery.

Background

The provision of mental health services is delivered within a policy context of the Mental Treatment Act 1945, Planning for the Future 1984, Report of the National Task Force on Suicide, Reports of the Inspector of Mental Hospitals, Criminal Insanity Bill, National Health Strategy “*Quality and Fairness A Health System for You*” (2001) and finally the Mental Health Act, 2001.

Since the publication of the Government Policy Document, *Planning for the Future* (1984) there has been a commitment from the providers of mental health services to transform the direction and ethos of services from an institutional base and focus, to one which is consumer driven and community-based. Evidence of this commitment can be seen in the development of appropriate community-based facilities and the multidisciplinary approach to service provision, which is integrated with other services, both voluntary and statutory. In the past number of years consumers, their families and carers have also been more involved in service planning and delivery and the development of consumer panels within various Health Boards, reflects a more inclusive change process.

The Expert Group on Mental Health Policy was established by the Minister of State at the Department of Health and Children, Mr Tim O’Malley in 2003, to prepare a new national policy framework for the mental health services. The Expert Group has undertaken to consult broadly and has invited the views of all concerned with the development of a policy framework for mental health. The Group identified specifically the need to elicit the views of the service user and relatives/carers and a questionnaire was widely distributed through the existing network of voluntary agencies.

The establishment of the Expert Group on Mental Health Policy indicates that there is now a need to update mental health policy, to take account of recent legislative reform, developments in care and treatment of mental illness and current international best practice and recognises that policy and objectives for mental health services are not static and need constant updating.

In spite of the commitment to update policy there are still limitations in the external environment with limited financial resources, the implications around the implementation of the Brennan, Prospectus and Hanly Reports and constant scenario of recruiting and retaining multi-disciplinary staff.

The terms of reference of the Expert Group specifically mentioned that a broad consultation be undertaken to inform the new mental health policy. A detailed consultation process was

undertaken, including a request for submissions, the hosting of two consultation days, one in Dublin and one in Limerick, and the posting out of questionnaires to elicit service users' views on mental health services. The members of the Expert Group recognised that there existed a group who for one reason or another may be unlikely to engage in this broader consultation process, and whose views may not be heard i.e., those in either acute admission facilities or those in long stay facilities. The Group commissioned the Irish Advocacy Network to engage with this group of service users.

METHOD

It was agreed that the Irish Advocacy Network would interview 100 service users currently using acute admission wards or long stay facilities. A questionnaire was devised for this interview (Appendix 1). This questionnaire included mostly quantitative questions, although respondents other observations and comments were recorded verbatim and included in the report.

These interviews took place in 8 of the 10 Health Board areas where the Irish Advocacy Network has a full time advocacy service in place. These are the Eastern Region Health Authority (x 3 Boards), the North Eastern Health Board, the Midland Health Board, the Western Health Board, the South Eastern Health Board and the Southern Health Board.

Members of the Irish Advocacy Network with extensive experience in interviewing clients in such environments were engaged to ask the questions and complete the questionnaires. To protect the dignity and integrity of respondents it was also decided that identities would be treated as confidential. The wisdom of this decision was borne out by respondents asking about confidentiality, as quite a few felt that responding honestly might have adverse repercussions if identities were revealed.

The methodology for selecting respondents was agreed and a policy to ensure proper safety protocols was followed. A copy of these was forwarded to either the clinical director or to the key contact person at each facility prior to the visit (Appendix 2).

The questionnaire was divided into eight sections.

SECTION 1: the demographic profile of respondents including age, gender, source of income, educational attainment and relationship status.

SECTION 2: admittance procedures and processes with particular emphasis on respondents knowledge and awareness of rights under the Mental Treatment Act, 1945 and amending legislation.

SECTION 3: addresses the subjective experiences of client's satisfaction with services.

SECTION 4: is dedicated to gaining a sense of clients understanding rights and formal complaint procedures.

SECTION 5: deals specifically with the amount of information clients receive in relation to their treatment e.g. diagnosis, care plans medications, treatment options, entitlements, benefits and housing.

SECTION 6: addresses issues of choice.

SECTION 7: focuses on the care environment in relation to cleanliness, quality of food, staff satisfaction, recreational facilities, personal facilities and money management issues.

SECTION 8 is a direct replication of questions 2,3 & 4 of the questionnaire posted out to all service users as part of the broader consultation process. These questions ask respondents opinions of what, if any, changes they would recommend in mental health services, what they think resources might be best spent on and what issues they would like to see included in a new policy for mental health.

It needs to be stated, prior to presenting the findings of this particular piece of work, that there were a number of factors influencing the outcomes of this consultation. In all instances prior to calling at venues, key staff were contacted and permissions requested to conduct the interviews. In all cases the key contact person in the first instance was either a Director or Assistant Director of Nursing. A number of senior clinical staff articulated some questions and reservations about the process and in all cases these questions and reservations were addressed to the satisfaction of all involved. At one particular venue the Clinical Director addressed any issues arising among clinical staff with a single proviso that the Mental Health Social Worker would accompany the interviewer in the facility and offer clients the opportunity to have the Social Worker present during interviews. In all cases participants agreed to have the Social Worker present. One consultant psychiatrist insisted on meeting the interviewer to clarify a number of issues. Without exception interviewers were greeted hospitably and afforded the utmost dignity and respect.

It also needs to be stated that the responses of those who participated are based on subjective experiences and that these experiences are valued and reported as real and valid.

They are a snapshot in space and time and are in no way meant to devalue the contributions of anyone involved in the provision of mental health services.

Generally, participants were selected by staff as those who, in the clinical opinions of staff, were probably best able to respond in a meaningful and purposeful way. Each participant was introduced to the interviewer and given a background to the Irish Advocacy Network and the Expert Group and the process. They were asked if they would be willing to participate and ensured of confidentiality and anonymity. Participants were also advised that if needed, the interview would be terminated.

The total number of respondents was 100, with varying degrees of response. Not all questions were answered and no pressure was put on anyone to do so. All information was recorded in written form on the questionnaires and transferred to a software application specifically designed by the Irish Advocacy Network research team which also carried out accuracy audits.

The research team held a number of follow up meetings to ensure that there was objectivity in presenting the findings.

THE FINDINGS

The findings following are presented under each of the eight sections previously described. They will show that there still exist anomalies between policy and application. The issues arising in this report are not new; lack of choice, lack of information relating to rights and treatment are common themes running through the report. Issues of poverty, not having meaningful occupation and housing and feeling isolated as a result of a period of mental ill health, reiterate the stigma associated with mental ill health. Over-reliance on medication and a lack of access to alternative treatments are also common themes highlighted. In spite of a commitment to develop community-based services, some people found that they received very little support after discharge.

It is important to note that this report is intended to inform the Expert Group in its work to develop a policy framework for mental health. It will constantly be stressed that there are systemic factors contributing to individual mental health wellbeing. In relation to the delivery of services, responsibilities lie not only within the Department of Health and Children but there are implications for other departments such as the Department of Social Community & Family Affairs and the Department of Education and Science.

Section 1

Personal Demographics

As this was largely a qualitative study there was no strict sampling procedure in place to achieve a representative sample of individuals in long-stay and acute psychiatric facilities. However, the demographic profile of the group of respondents shows that a very good spread of individuals was interviewed, in terms of gender, age profile, relationship status and area of residence.

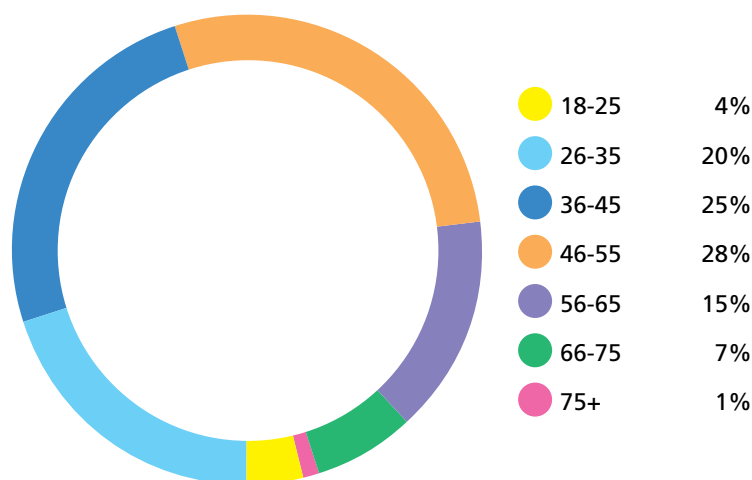
GENDER

There was no preconceived agenda in terms of achieving a gender balance, it was coincidence that the gender breakdown turned out to be 50 male and 50 female.

AGE

A breakdown of the age profile of respondents is given in Figure 1. The largest proportion of the group was aged between 46-55 years (28%), followed by the 36-45 age group (25%). The age profile of this group of respondents is similar to that of all admissions to psychiatric hospitals and units reported by the Health Research Board for 2002¹.

Figure 1: Age profile

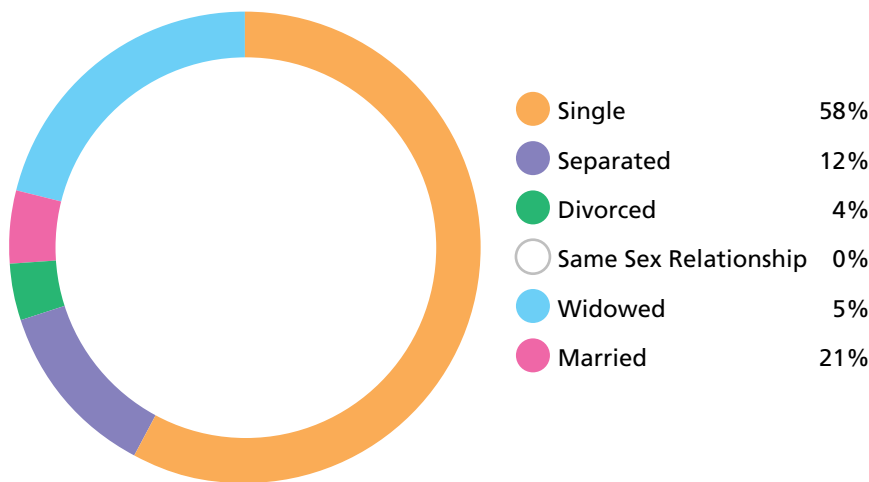


¹ The two biggest age groups for admissions in 2002 were 45-54 (20%) and 35-44 (22%) (Daly and Walsh 2003).

SIGNIFICANT RELATIONSHIP STATUS

58% of the group was single (Figure 2). This high proportion of single people is also reflected in the profile of people admitted to psychiatric hospitals and units, where 54% of all admissions were for single people in 2002.

Figure 2: Significant relationship status



MAIN PLACE OF RESIDENCE

Most of the people interviewed lived in towns or urban areas. There was a good spread of individuals from all types of areas.

Area	Total Number
Rural	24
Village	8
Town	37
Urban	31

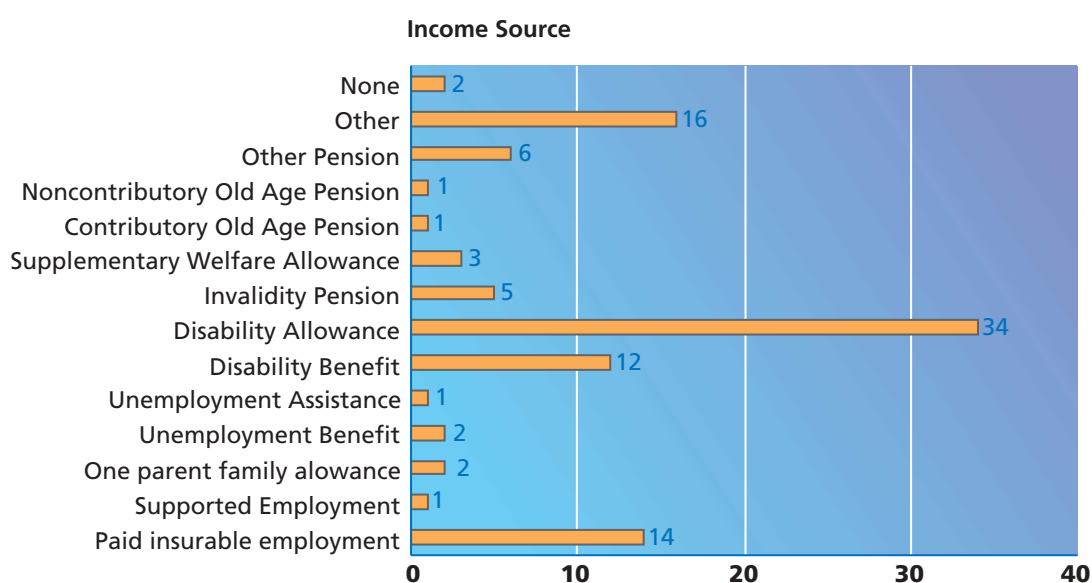
MAIN SOURCE OF INCOME

The levels of income for this group are worrying. Figure 3 shows that 68% of respondents depend on welfare payments of one sort or another, 30% are in some form of employment but there is no data to gauge levels of income, 2% of respondents have no direct income and are dependent upon either family or spouse. The average payment for a person on

welfare is €138.40 per week. This finding highlights issues of poverty and its correlation to mental ill health. Using data from the ESRI and the CSO, CORI estimated that the relative income poverty level for a single person was €180.30 per week².

“People who live on low incomes are more likely to suffer poorer health, experience more psychological distress and generally lead shorter lives than those who are more affluent.” – Combat Poverty Agency.

Figure 3: Main source of income

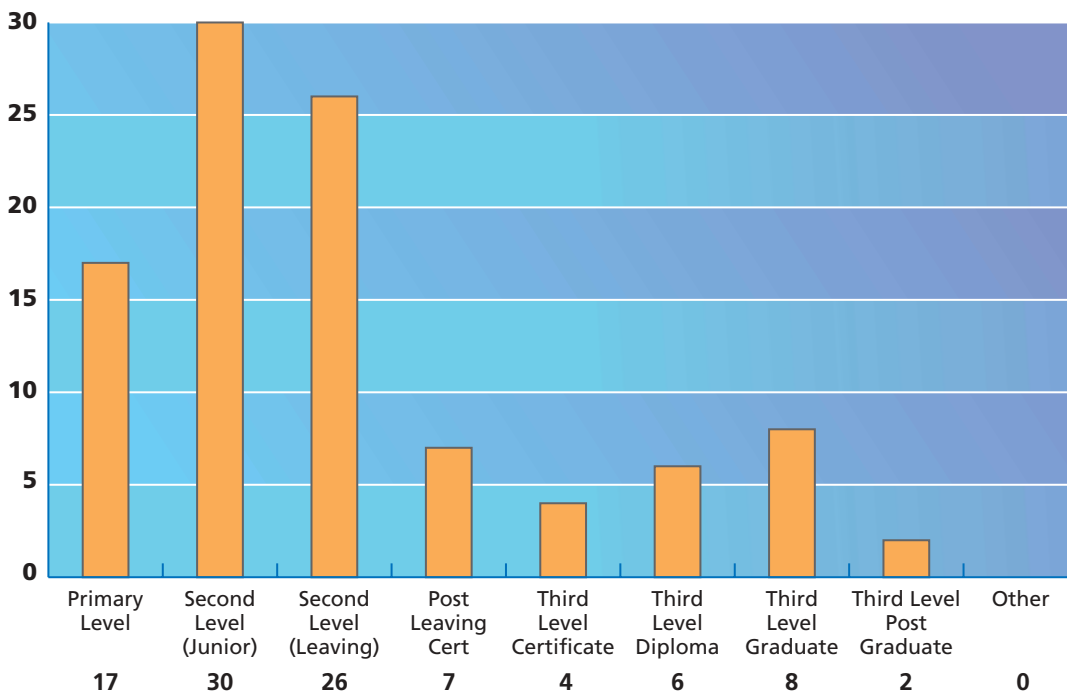


²Commission's Socio-Economic Review 2004: PRIORITIES FOR FAIRNESS: Choosing Policies to Ensure Economic Development, Social Equity and Sustainability. C.O.R.I. 2004

EDUCATIONAL ATTAINMENT

The level of educational attainment for this group of service users was generally good, with just over half (53%) educated to leaving certificate level or higher. However, the remainder had a junior cert qualification or less.

Figure 4: Level of educational attainment



Section 2

Admittance procedures

Respondents were asked a number of questions about admittance procedures and some interesting findings arose. When asked if people felt they were admitted to hospital when they needed to be, 77% said that they were. The physical surroundings of the admission/reception area were said by 66% to be comfortable and private.

There is a huge deficit regarding people's access to and understanding of information relating to their rights under the Mental Treatment Act, 1945 and amending legislation, at the time of admission. A staggering 88% of respondents said that they did not receive any information regarding their rights under the Act. It could be argued that when people are being admitted that they may not be in a position to understand this sort of information, but when asked if they subsequently received information on their rights under the Act again a phenomenal 90% responded no! When asked if people understood their rights under the current legislation 77% replied that they didn't.

However, other aspects of the admission process were more positive. 72% of respondents indicated that they were introduced to those who were going to be responsible for their care. 91% knew who their treating consultant was and 87% said that staff in facilities were clearly identifiable. When asked if clients felt that they had reasonable access to nursing staff 79% said that they had and 74% indicated that they felt they had reasonable access to their consultant the other members of the multidisciplinary team.

When questioned as to whether people felt they were treated with dignity and respect 82% said they were and further 70% indicated that they had adequate privacy when being interviewed by staff.

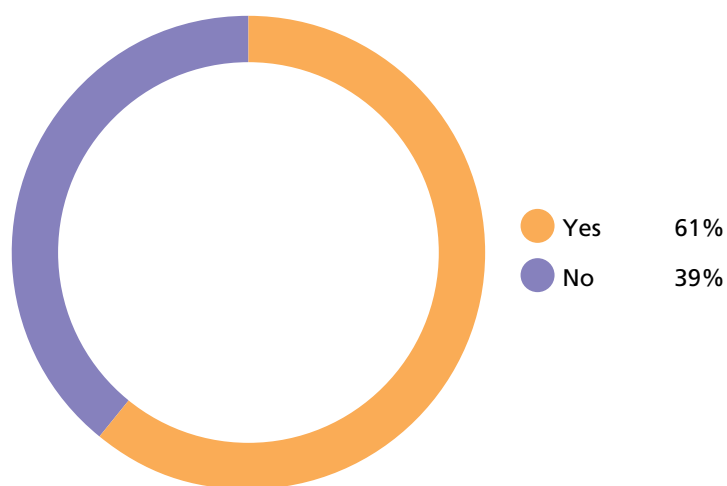
Section 3

Service Satisfaction

Approximately two thirds of those interviewed indicated that the services being currently provided are meeting their needs (Figure 5).

Figure 5: Satisfaction with service

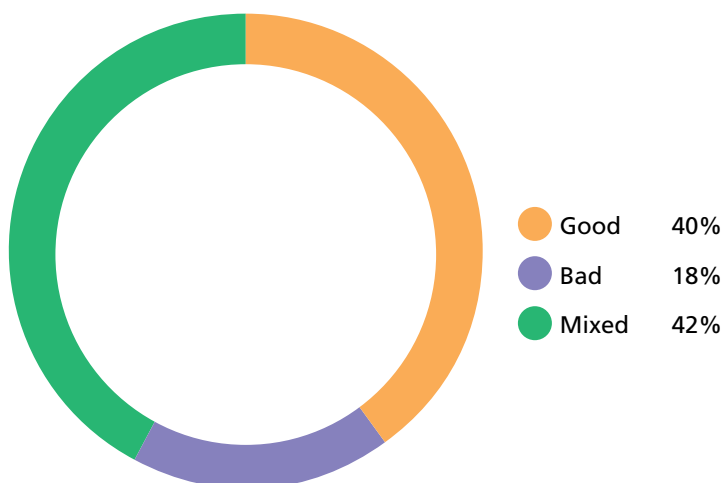
Do you feel the service being provided is meeting your needs?



When asked whether recent experiences of mental health services had been good or bad or mixed there was a varied response.

Figure 6: Recent experiences good, bad or mixed?

Have you recent experiences of mental health services been good, bad or mixed?



When asked “what made your experiences **good**”, the most striking responses were the level of supports that people experienced from consultants and from nursing staff in particular:

“Nurses are very good, can’t do anymore, always there. Very good to me, couldn’t do any more for me.....the staff and nurses are very helpful.....nurses are kind and helpful and doctors are doing their best -key nurse makes things a lot easier for me.....nurses are fantastic, cater to everything, not just medical. They know services aren’t there, try to compensate for this given support you need.....” - nurses were very helpful and kind.....“The nursing service is very good, the nurses are everything..... find nursing staff exceptionally good.....Nursing staff make you as comfortable as they can..... the nurses are very good if I ask anything.....Safe and feelings of being looked after.....After hospital I found there was good support to help me to get my life back together.....the professionalism of the psychiatric team, including doctors and nurses, the catering staff, administrative staff, the occupational therapists and the general facilities of the hospital, including the outdoor facilities.....The consultant took an interest in welfare, both mental health and general health needs.....any questions I have are answered, get everything I need.....treated as human beings.”

Improvements in care environments also contributed to peoples experiences being good:

“-the place is clean and spotless and the food is good..... recently moved from hospital to a new purpose built unit and it has made a huge difference to my life. More relaxed a huge improvement on what they were. I got an Indian head massage the other day, it was very relaxing.....in the beginning things were bad, now living In the hostel things are much better.....I'm sick and can't cope at home and when I'm well I go home.....The hospital is a better place to be when I am unwell.”

Having access to an advocate also helped people feel positive about their care:

“I think the advocacy service is great, knowing that the advocate has personal experience of mental illness it is very easy to talk to her as I know she understands. Also she gives great hope to people as she has made such a good recovery. She is an inspiration to everyone.....The help and support of the peer advocate who takes the time to listen and treat me as a fellow human being. The help and support of the other patients. We all support each other and try to raise each others spirits when I wanted to see a doctor I could see one, good structure and support.”

When asked “what made your experiences **bad**”, there were criticisms pertaining to treatment methodologies being aggressive and invasive, the over use of medication and its debilitating side effects:

“-being locked up here against my will. Being forcefully medicated.....Too much medication on first visit.....

Treatment aggressive. Staff became irritated by symptoms, left in bed for a month without any staff contact. Diagnosis given in a demeaning manner, meds not explained.....the drugs have taken away all my feelings; I have no feelings since I started taking them. I am just dead inside, all the service offers are drugs that alter a person’s thought processes and if you don’t take them you are forced to take them.....- being held here against my will, no respect. Being forcefully medicated. I am here for over 4 weeks now and my doctor has been on holidays for 2 weeks. I have only been seen here 3 times in all. I am an outdoor person and I am locked up in here with no access to the outside. I am cracking up. the medication is not suiting me, it is making me drool all the time and that is very embarrassing, my basic human rights are being violated. I have asked to sign a voluntary form, but they won’t let me.....Some hospitals treat me like a complete idiot, have control over you and your body. If you express anger you are sedated. When I refused medication I was forced with depot.....put into cell (single room) and injected against will.....the drugs were too heavy.....I was given injections without reason or consent. I was dragged to a room and injected.”

There were some negative statements in relation how people are treated by some staff:

“-left in limbo, not given any information about what is happening-being abused by doctors and nurses. Given injections and nurses don’t care or try not to hurt, no choice as to injection.....nobody ever asked me what I needed, rather I was told what I needed.....Some staff are bullies, I just need someone to listen.....staff too busy to listen to you, some of them are also abusive. I regularly get pushed around or dragged out of bed. The other day there was a female patient lying on the ground and a male nurse came over to her and kicked her to get up.....my consultant won’t listen. She only sees you when she wants to and you may be talking to her- even in the middle of a sentence and she will say interview over and block her ears with her hands and push you out of her office.....Some nurses are abusive -verbally and physically.....Some nurses are really bad especially some of the nurses on night duty the way they talk to you (shout), laugh at you and generally push you around.”

And while not as serious as the previous experiences the following would also be a cause of concern:

"-nobody explains anything, it is worse than school.....Felt unable to express my needs, some of the staff would brush you off.....felt that I was treated as a label and left to students.....nurses over-worked, can mistake you for someone else. I was mistaken for someone who was bringing in tablets and never apologised to when this was found out to be untrue. It was upsetting; especially when it was my first day.....another patient threatened to rape me."

Service users constantly requested the need to be listened to by someone with a caring attitude:

"doctors, nurses are doing what they can, but nothing they are doing is what I want.....my CPN - no positive rapport, negative rapport.....I cant spill my guts out there is no one there to listen if I do.....not enough time spent with doctors - expected psychotherapy, too much medication and not enough talk therapy, all I was given was a few tablets and moved around, now there seems to be a bit more than tablets."

In some cases there was a reasonable analysis on behalf of service users as to why they felt they were receiving inadequate care:

"-geriatric patients make all the demands upon staff.....When nurses have finished attending to geriatric patients, they have too little energy left for the rest of the patients.....It seems crazy to be treating people with addiction problems with mental health patients.....People with alcohol problems should be treated in separate facilities."

Some respondents stated that proper community support was not available to them after discharge and this meant that they had to come back into hospital:

"-this is my third admission in the past year and while the inpatient care is very good there is no real support in the community after discharge other than the out patients clinic.....there are little or no social supports."

Other reasons why interviewees claimed their experiences were bad were because;

“there are no activities.....I cannot believe that in this day and age such stone age services exist.....normal day to day was long and boring..... Can be daunting for visitors, like coming into an asylum, locked doors puts visitors off. The corridors could be more cheerful, playthings for children. Family room secure environment for children visiting. Still very clinical.”

The level of care and commitment from staff has been highlighted as contributing to people's experiences of services being positive as has been the improvements in facilities. Another issue which contributes to people having positive experiences of the services is having access to an advocate.

The flip side of people's positive experiences of staff is that some of those interviewed stated that the treatment they themselves had received or had witnessed from staff was quite frightening. There were allegations of abuses and bullying by staff although these allegations may reflect a low percentage of people's experiences, the fact that they are happening at all is worrying.

While not all the negative experiences articulated relate directly to the previous serious incidents the lack of common decency and respect for other human beings is another criticism levelled at some staff members.

Service users spoke constantly about not being listened to and having no input to any aspect of their own care and treatment. There is an over-emphasis on medications and a lack of facilities for activities while in care and a subsequent lack of community support after discharge.

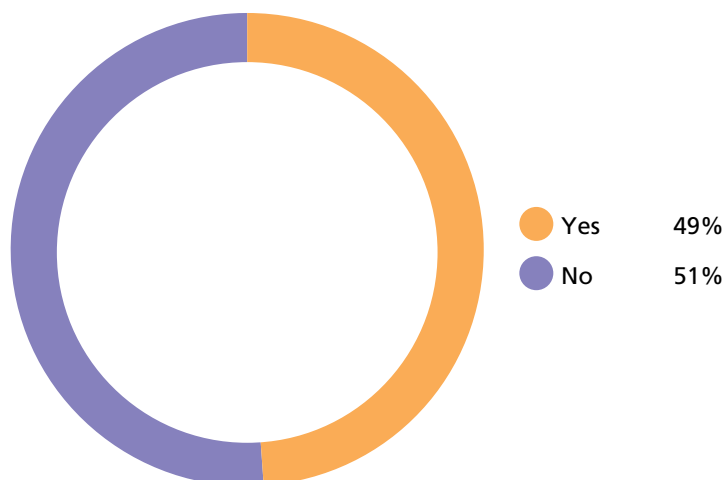
Section 4

Complaints and Complaint Procedures

When asked whether people felt that their care environment was restrictive, 51% said it was. People were asked if they were aware how to make complaints if they felt dissatisfied. While almost half the group (Figure 7) were aware of how to make a complaint, only 29% of those questioned knew what their personal rights were within the services. When further questioned as to whether any member of staff had informed them as to the procedures for complaining, 85% of those questioned replied no. A further 69% stated that they were not aware of any rights they had with regard to refusal of treatment and anecdotally people stated that you had to do what you were told or else.

Figure 7: Awareness of complaints process

Are you aware how to make a complaint?



One third of those interviewed had made either formal or informal complaints and in the majority of those cases the outcomes were not at all positive:

"-brushed aside..... if you make a complaint against a staff member it goes nowhere.....I have made informal complaints which went nowhere.....I have made formal complaints and was happy with response.....I'd be afraid of backlash.....Nurse assaulted patient, written complaint, no response.....if I complain to staff I am fobbed off, if I write a complaint I hear nothing back.....I was told not to be bothering the nurse- put off..... I filled out one of the complaint forms and I got an acknowledgment of it, that was months ago and I haven't heard anything since..... I complained to my consultant the way some of the night nurses treat me and the other patients and all he said was 'that's all in the past lets forget about it..... you only get

treated worse, my mobile was taken from me after complaining..... when I was pregnant I was given medication which debilitated me, I complained but never heard anything..... very defensive from person I made complaint to..... if you rock the boat you may be penalised, staff have complete control over your life..... feel that they'd say he's sick, leave him alone.....Doctor didn't take me seriously..... you are blackmailed into taking meds..... about 6 nurses cornered me, held me down and injected me. I don't know what they gave me but I was out cold for about 6 hours..... was called a spoilt child, when I made a reasonable request. I was told the nursing staff run the ward.....-sent letter to solicitor asking about legal entitlement re money and diet, when doctor received letter from solicitor client had 15 minutes of ranting, medication threatened, doctor said he was debating further signing of temporary form. But this action made up his mind and was further committed for 6 months.....I didn't get a fair hearing, they knew who I was and my background..... the complaint was taken seriously and outcome was appropriate..... nobody came to me with feedback"

A huge deficit was identified in relation to those questioned knowing what their personal rights were within the services especially in relation to the refusal of treatment and some people either felt bullied or had no options in relation to treatments. Little or no assistance seems to be in place for people to make complaints and a culture of disincentive appears to be the implicit policy.

Only 34% of those who had made a complaint felt they got a fair hearing.

Section 5

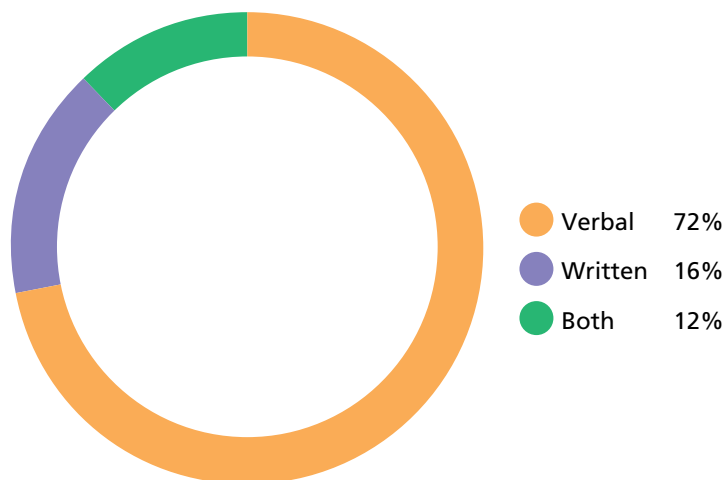
Information

During the interviews there were a number of anomalies regarding the information given to patients as to what they were being treated for. Only 46% received any information and only 61% of those interviewed had been given any form of diagnosis. Again anecdotally there were a large proportion of those interviewed who felt they were being treated for “the old nerves”.

What is worrying though is the lack of information provided to patients about their medications either in terms of the benefits or any side effects that may be experienced. Only 24% of respondents had been given information about their medication. Figure 8 shows the different ways that information about medication was given.

Figure 8: Methods for giving information about medication. (This graph relates to the 24% of respondents who had been given this information).

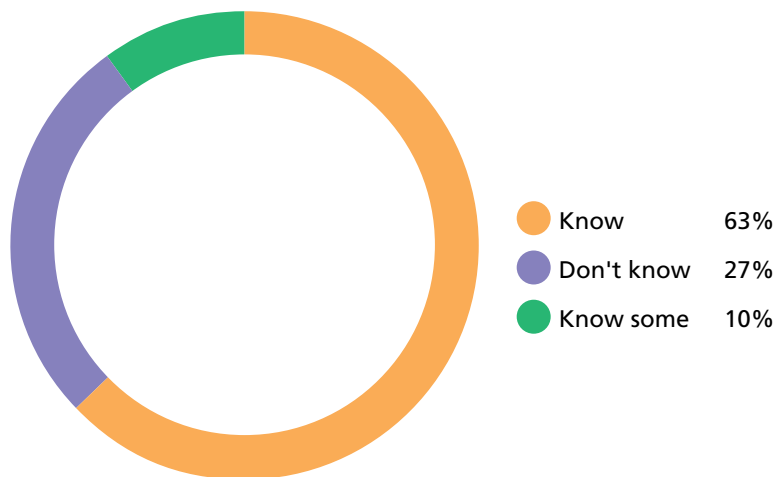
Was this information given to you verbally or in written form?



All respondents were asked their knowledge of the medications they were currently taking (Figure 9). More than one third did not have full knowledge of the medications they were on.

Figure 9: Knowledge of current medications

What medications are you currently taking?



Of those who were provided with information about their treatment and medication 72% stated that they could understand this information.

In relation to a care plan only 29% of those questioned were aware that such a thing existed and only 32% were involved in any discussions about their own treatment plans and a further 62% indicated they did not have enough time to consider their treatment options.

A fifth of those interviewed were not able to access their benefits and entitlements when in care and a further 18% did not have access to their accommodation.

When asked as to whether a person had availed of ECT as a treatment 32% said that they did, but of this group of people only 53% had given informed consent to having this form of treatment.

The lack of information provided to patients regarding what it is they are being treated for as well as information about either the benefits or side effects of medication is a major concern.

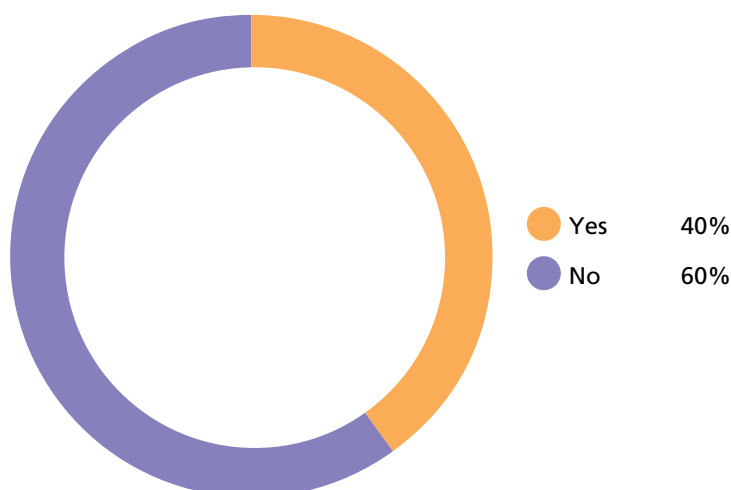
There are also clear deficits of information relating to care planning. Over 70% of respondents were not aware of any plan in relation to their care and again over 70% had no input into their own treatment plans. These figures suggest that within mental health services the majority of service users are passive recipients of services.

Section 6

Choice

Only 40% of those questioned felt that they had any choices within the current services (Figure 10).

Figure 10: Choice
Do you feel you have “Choice” within the services?



Some of the testimonies of those who responded yes include;

“-take or refuse medication..... to be a vegetarian, to eat meat or be a vegan..... To attend O.T. or not..... To attend an outside facility or not.....To spend my money as I please. To smoke within designated areas.....I can come and go when I want.. happy here new building, comfortable, near my family.....I do my work and come and go.....choice to refuse or accept what’s offered.....I could go back to my work I have my clothes I can go where I want e.g. AA meetings..... more choices than received in London I can lie down when I want to, they don’t call me until 8.30-9.00.....encouraged to mix and go out to play cards, has been offered psychologist.....you can take it or leave it if not feeling well, can ask for a nurse to talk to, or even a doctor. Whatever is going I have to take it I can make up my mind as to how I put my day in.....good food, conditions excellent freedom to come and go.....I can go to work and at weekends have a lie in.....there are just basic services you take it or leave it.....seen every day for a chat and there is a planned approach to my illness.”

Those who responded no were asked what choices they would like to have;

“ less medication, might need medication at times, but not constant.....attend during the day in one hospital the doctor was a total autocrat and I had no voice or choice....., like to be able to choose my own doctor.....counselling service, different therapies. To get out and get one bedroom flat would like more freedom to go to town, feel less like prisoner, more access tohomelike environment, less restrictions on visiting..... would have liked to have been informed of the different types of treatment available the choice of doctors..... I don't like my doctor and she doesn't like me but I cant change.....it is take or leave it.....to be able to have a life like everyone else, it is too strict, should have more freedom. I cant do anything I have to ask permission for everything, I am a person, nobody, nobody sees that. If I were seen as an adult human being it would be a start once they get you on meds, its very hard to go back.....would like to have more information on illness and medication.....would like to have been told what the problem is and what interventions are available.....there should be counselling and psychologist to give greater help to patients freedom to take a walk etc let rest for a while, food not great.....I would love to be able to dump meds..... relaxation, counselling and art..... everyone else seems to have power over you I would love to have access to a counsellor who has never met me before..... more choice of treatment, over reliance on meds, more counselling, where I went to hospital, who my consultant was, choose primary nurse.....to be informed about meds and make choices.....choice over counsellor.....professionals laid down plan and I didn't have any options would like to move about accommodation more money to be able to make my own decisions talk longer and better to the doctors, more of a say in medication outside of going to hospital where I don't need to be.....more freedom to come and go, to be trusted.....no acceptance for diversity- majority rule. Home based care as available in other areas.....The right to refuse the drugs that cause debilitating side effects.....The choice to articulate what I feel may be the problem and assistance in finding a solution in hospital..... limited choice you seem to be there for what others want.....Would have liked more choice over medication, maybe other ways of treatment without as much side effects.”

83% felt that they were able to articulate their own needs and wishes, but the responses they received varied;

“-crap.....“brick wall generally negative response..... feel fobbed off sometimes..... I get what I want..... you are told that you are unwell..... oftentimes nobody wants to know....you are told that you are ill and therefore unable to know what you need.....sometimes positive.....taken seriously..... again its like you are a child and someone knows what’s best for you.....I get a good explanation.....don’t ask for much, leave things to their discretiondepends on the nurse.....good response they do their best for you.....medication increased, privileges withdrawnI am taken for serious.....depends on whether nurse is in good or bad form.....they laugh at me.....I'm not taken seriously,..... they sneer at me and treat me like dirt.....the response I get is positive.....mainly fair staff are considerate but the people are not there to listen.....told to wait a minute and he will see me- but they don’t..... very little taken seriously people don’t seem to want to listen to what I say.....requests taken seriously a fear of repercussions if assertive.....helpful I get a fair responseI was very angry once and I expressed it with negative consequences.....Consultant also gives a lot of time. if I want to make tea I can I am taken seriously dr. made the decision to cut meds, and didn’t change her mind.”

Those who responded no were asked what they felt might help them;

“better liaisons between key worker and doctor.....a complaint form..... sympathetic ear.....empathetic ear, an advocate..... have committed myself to this environment and go along with what is recommended, friends are helpful when I am really unwell to know that I would be listened to.....you are trying to prove to the medical staff you are improving and to welfare that you are still unwell to retain your benefits.....classes on self-confidence, if there is I would be interested.....better management and control by nurses know that it is safe to do so and to know that I wouldn’t be punished for doing so..... constant communication and discussion with nurses.....More dialogue around meds.....independent voice.....I need someone to help me to get the doctor to listen to what I want.....I just want someone to help.”

Section 7

Environment

In relation to the mental health facility people were currently using, a number of questions were asked and the following responses were given:

Clean	Yes	89%	No	11%
Good quality of food	Yes	82%	No	18%
Choice of menus	Yes	63%	No	37%
Adequate portion size	Yes	97%	No	3%
Meals provided at socially acceptable times	Yes	77%	No	23%
Friendly atmosphere	Yes	88%	No	12%
Good recreational facilities	Yes	52%	No	48%
Accommodating to your views and beliefs	Yes	76%	No	24%
Courteous staff	Yes	89%	No	11%
Variety of daytime activities	Yes	40%	No	60%
Choice of daytime activities	Yes	32%	No	68%
Private bathing facilities	Yes	82%	No	18%
Single gender toilet facilities	Yes	95%	No	5%
Access to smoking and non-smoking areas	Yes	96%	No	4%
Access to private outdoor space	Yes	80%	No	20%
Access to public telephone	Yes	95%	No	5%
Adequate facilities for visitors	Yes	64%	No	36%
Have you access to personal hygiene requirements	Yes	88%	No	12%
Place to secure personal belongings	Yes	70%	No	30%
Do you take charge of your own income?	Yes	75%	No	25%
If no, is it managed by a member of staff or family?	Staff:	66%	Family:	34%
Are you satisfied with this arrangement?	Yes:	89%	No	11%

Generally the responses showed a high level of satisfaction with facilities. The main areas where services were lacking was in the choice and variety of daytime activities and lack of recreational facilities.

One of the limitations of the methodology used during this process is that service satisfaction scales were not used.

Section 8

General

People were asked what changes would have the greatest benefit for their mental health and well-being. Respondents were encouraged to be imaginative and innovative. Over 300 suggestions were made and these are presented below, collated under separate headings.

RESPECT & CITIZENSHIP

In 2004, there are still some serious equality issues associated in using mental health services and the basic levels of dignity and respect afforded to service users.

“an end to involuntary admissions.....when you are being admitted in A&E, more dignity should be given.....stop everyone making it hard.....Your trying to prove to the doctor your getting better and social welfare that you are sick.....I feel that nursing staff should speak to patients as human beings..... they speak down to people.....a more humanistic approach..... treat people with respect not as second class citizens.....more right for women- nurses male/female think they can restrain/assault me.....educate staff on some basic principles of treating people with dignity and respect.....to be treated with dignity by nurses and doctors.....to be treated as an equal human being by all and treat all people with real respect.”

COMMUNITY MODELS

Respondents continually spoke about various aspects of community mental health. These varied from basic improvements in existing community services to developing more innovative community-based services. Having a place to go to as opposed to hospital was also a change that people were asking for as well as stating that the process of hospitalisation removed one further from ones community and made reintegration harder.

“more support in the community to help overcome isolation after discharge.....let people go home and be treated at home.....a place that I could go for a few weeks as opposed to hospital.....more CPN's.....services should be more community based, lessening the need for hospital.....a living complex with low support for independent living.....freedom to make tea/coffee or snacks and have a place like your home where you can go.....treat people in their communities with as little disturbance to their lives as possible.....a halfway house where you could go if you were slightly unwell.....a facility or a house where I could go without having to come to hospital.....social outlets for recovery, outward looking half way house, bedrooms with en-suite.....community environment- garden and trees.....more community

support, non clinical.....day facility- without stigma, help rebuilding ones life.....stepping stone for re-integration.....I would like to have somewhere to go for a break, instead of hospital.....every time I feel unwell its off to hospital, that makes it worse and the thing goes round and round but never improves.....a better pre-discharge plan to make the transition from hospital to home easier. If a person was discharged gradually it would reduce the rate of readmissions. Have more community supports to help combat isolation. I didn't go back to work after discharge the last time because of problems there and was at home alone all day. I think that if I had something to do or somewhere to go by day I wouldn't have needed this admission..... close the hospitals and house people in the community.....make unit more homely, less clinical.....good out-patient support care.....more social workers, family therapists, counsellors, occupational nurses. Access to meaningful occupation and support in the community, listening ear, support groups and give people who have become institutionalised intensive support to help them re-integrate back into the community.....more help after discharge to get involved in activities with the 'normal' community and get away from hospital model of treatment.....better local services, acute facilities in normal community settings.....day centres and clinics held in the community not in hospitals”

ACTIVITIES

A significant amount of people who responded commented on the lack of activities that exist in current care environments and where there were some activities these were often meaningless occupations. Facilities for exercise are also high on the priority list of changes people want to see, e.g., access to gymnasias and swimming pools as well as a day centre with activities and recreation, art classes, writing classes, task skill, discussions, pottery, craft were just some of the suggestions.

“a gymnasium and fitness facilities.....to have meaningful occupational therapy in the hospital.....day trips and more recreational and daytime facilities.....structure and daytime activities.....recreational facilities within hospitals, a choice of daytime activities.....more leisure and therapy.....aesthetic surroundings.....more choice of indoor activities.....more activities and classes.....to have a treadmill on the unit and an exercise bike where people could get some physical exercise..... more meaningful than sitting around smoking.....more things to do while in hospital and more things to do during the days.....a day centre with activities and recreation, classes + art classes, writing classes, task skill, discussions, pottery, craft.+ anything to occupy patients mind and take them out of day room.”

MEDICATIONS

There were also many suggestions around medication and its perceived overuse. Interviewees stated that there was too heavy a reliance on medication and very little information provided on alternatives.

“get away from the over emphasis on medication.....too much experimentation with medication..... there is only medication, surely there is something else.....less use of medication and use peoples stories.....stop giving out so much medication.....change the emphasis from medication to more holistic interventions.....creative recreation and get away from meds.....to end forced medication.....more facilities for activities, computer, woodwork and less medication.....over reliance on meds..... explain side effects..... More counselling, choice of treatment, get more information in regard to the medication.....greater breakdown on drugs therapy, administer medication if people are really in bad health.”

STAFF

Reviewing staffing procedures is another area of change that would be welcome. Training and having nurses available specifically to spent time listening and being with patients was considered to be important. Redefining roles and allocating staff specifically to geriatric services was something patients felt very strongly about.

“doctors and nurses to take obligatory courses in people skills and in communication skills.....nurses should have a more therapeutic role rather than domestic.....more staff- time dedicated to geriatric needs.....nurses should have aids for domestic and geriatric service.....more staff - nurses, OT's.....more input from nursing staff they seem to be taken up a lot of the time with admissions and have little time for patient”

ADDICTION SERVICES

Addiction services combined with mental health services caused further distress to people.

“separate services for addiction and mental health service users.....separate drinks/ drugs from mental health services”

ETHNIC MINORITIES

The growing ethnic diversity that has occurred in recent times is not being reflected in mental health services. The one size fits all is not taking into account the needs of people from different cultures.

“the food is not culturally appropriate to non-nationals”

SELF DETERMINATION

There is a desire to see changes in the way services are delivered. People felt that currently services are paternalistic and that the patient has little or no say in how they determine themselves. Rehabilitative work and training are all geared toward entry level and a feeling of being patronised by the professionals prevails. There is also a feeling that the goal of professionals is on compliance and in some cases a breaking of the persons will.

“more funding for voluntary self help user groups.....to have some kind of meaningful occupational therapy in hospital, and to have my own place and a course and work.....to have mutual peer support to assist me live with a mental illness.....I'd get people seen to quicker, proper jobs support the rights of patient to determine medications.....to be able to go places when I want, even accompanied.....people not being locked up against their will.....more freedom of movement and more facilities.....more autonomy and independence for patients..... Not holding people against their will.....put an end to all involuntary admissions.....I would like to know where my children are and have access to them.....I feel I am normal but have a few difficulties, they try to convince me I am sick, I should be the one who determines that”

HOUSING

While over 80% of those interviewed stated that they had adequate accommodation prior to discharge, there are two areas where it was suggested change would be welcome. The first is the need for housing for those who do not have their own accommodation and the second is for a more independent living environment for those who are dependent on family for their housing needs.

“housing needs to be provided for, not happy in hospital.”

COUNSELLING

By far, the greatest change that people who took part wanted to see is a move toward having more counselling, psychotherapy and other talk therapies available as part of the treatment package, not just in the hospital but also in the community.

“to have talking therapies available in the community. I had a problem with bullying at work and as a result I became paranoid and thought I was being bullied in every area of my life..... I can talk to the doctors here or my key nurse about it but there is no one to talk to after discharge.....more counselling.....I would love to have someone I could talk to and who would listen without putting me in a box.....more access to talking therapies- psychotherapy and counselling.....I would love counselling..... more counselling needed to get away from pill popping especially in GP clinics..... A dedicated specialist in GP surgeries to deal with mental health issues.....less meds..... more counselling for people who are in serious need of personal assistance other than medication.....formal counselling service, help and advice..... a broader range of community services- e.g. counsellors therapists etc.....address the social exclusion associated with mental illness.....more psychotherapy, alternatives to medication.....replace drug therapy with psychotherapy.....need for psychotherapy and group work.....counsellors for addiction as part of ongoing treatment.....to have access to a psychotherapist or a counsellor who was prepared to give you time and listen to you.....I attended a counsellor prior to admission and she was far more beneficial than the medication”

ALTERNATIVE TREATMENTS

Respondents want access to more alternative therapies i.e. yoga, acupuncture, music therapy.

“more alternative therapies i.e. yoga, acupuncture etc.....music therapy.....patients given a choice, e.g. Prozac or St. John’s Wort.....if people are improving offer alternative treatments.....I would get alternatives therapies, chiropractors etc.”

MODERNISATION OF FACILITIES

Another area of change that people who took part want to see is the modernisation of premises with basic facilities, e.g. “showers and baths and things that people normally have at home” coffee shops, open spaces, fresh air. Food and diet need to be looked at as well as the need to get away from the institutional facility model of care.

“I am an outdoor person and I am cracking up in here.....larger wards, more space, individuals room like a normal place a person would have at home, more homely environment.....open the hospital as a hostel.....the food needs to be changed, everything about eating is institutionalised and there needs to be choice and better quality of food.....the set-up is institutional, therefore change is limited.....more modern buildings.....re-heated food is not acceptable,be more selective in choosing nursing staff, some are fine but others are only here for the money..... close big institutions down, replace with small units in community with modern facilities.....food freshly cooked, presented in a dignified manner. Categorise people and accommodate them appropriately.....break down the old facilities, modernise building.....do away with these old buildings..... Once you come here you are seen as mad or insane it goes back to the old days”

EDUCATION

Education was a change that was spoken about but one that has many dimensions to it. It was suggested;

- that professionals need to be educated about the patients perspective,
- that mental health needs to be included in the second level education curriculum,
- clear and unambiguous information on the new Mental Health Act, 2001,
- that education campaigns be used to tackle stigma ,
- that patients need access to second chance education opportunities.

“have mental health included in curriculum.....the new mental health Act should be properly explained to members of the public, in a reasoned, well stated and responsible fashion.....more explanation about why the person is here (hospital) and what part of the behaviour is unacceptable.....I'd like to have all my facts done right, there is too much confusion.....more information on mental health for the wider public to lessen stigma.....more understanding for GPs of depression.....through strong advertising, take the sting out of stigma.....Classes – English, etc. computers.

Self-esteem and confidence.....fear of stigma on discharge,- better education to remove stigma.....to know more about the multi-disciplinary team to a better understanding of how there teams work.....more personal communication with patient and therapeutic agent, information.....classes to occupy time.....use high profile personalities to publicise mental health..... promote positive mental health, support groups..... more training and work, get me away from doing nothing.....employ more staff to develop a continuing rapport with clients and to listen.....education of the public about mental illness. There is still a huge stigma associated with it especially in rural areas where everyone knows everyone else.....we should get another chance at education when we are well.....more information in regard to treatment received and education around mental health issues for the general public.....get rid of stigma.....publicity campaign showing that anybody can be hit.....communication between staff and service users is not good.....have other staff whose time is dedicated to patients only”

SERVICE USER INVOLVEMENT

An overriding change that people who took part want to see is for more involvement from service users in delivering services.

“have a say over who I live with in hostel and have a greater say over other residents in the hostel.....if I were trained to work in the system I would be able to care for others.....public awareness campaign about mental health from the patients perspective.....have patients trained to run services.....public education from the patients perspective not the clinical perspective.....former patients would be better to run services, we know what people want.....have patients who are better work in the hospitals, we know what it is like.....group sessions between patients and staff to air views, to evaluate how service users feels the service is going. Doctor rota so service user knows what doctor is on duty. These ideas would give a little bit of control back to service users.”

EXTRA RESOURCES

When asked, if extra money was to be invested in mental health, what in your opinion should the priorities be for spending that money, a lot of the responses replicated those that were suggested as changes that people would like to see. The following are suggestions not already articulated.

“family support.”

“housing for people who are not in a position to provide their own.I would fund facilities for the homeless who are using mental health services..... should be houses, not hostels where people can live in freedom with some support..... housing- especially for mental health service users..... spend money on independent living accommodation in a supportive environment to have supported housing in the community for people after discharge”

“Research into different areas of mental illness as some people seem to be written off..... more research into mental health as to why people have mental health problems in the first place, more research into medicine, more therapies and choice of therapy, recreational activities within the hospital”

“Educating users of the service to get more skills..... to develop systems e.g. educational system to meet needs of users rather than users fitting to meet the needs of the system..... Let the public know that patients are not dangerous.”

“Half way house rather than hospital.”

“ Employ people who have used services to work in services.....people with personal experience would understand better and you could relate to them.”

“ If the money that is used to keep people in hospital and the money used for drugs was used for psychotherapy, the cost would be less and the benefits greater.”

“to have more advocates to support people when they need support.....If there were more advocates, more people could avail of the service. I think that while this may need investment initially it would prove cost effective in the long run as it may cut down on the readmissions or the amount of medication used.”

“let more patients become involved in how resources are spent.”

“Real jobs.”

MENTAL HEALTH POLICY

Finally respondents were asked to express their view or to articulate any proposals they had for the new Mental Health Policy?

"..... an ombudsman for mental health."

"The patient is at times at the bottom of the communication thing. Change this."

"Change the law so patients are not threatened into compliance, patient threatened that status would be changed from voluntary to temporary if she tried to discharge herself. More information on the system."

"Mental health policy has not moved with the times at all, more interventions before a person comes into the hospital would help."

"...the stigma of being a service user and not having work affects my own esteem."

"...people coming to Ireland from overseas are being treated in ways that leads to mental ill-health."

"Education - more around mental health, more openness would remove stigma."

".....encourage more freedom and independence for patients."

"A person with a mental illness should be treated with respect and dignity just like anyone else. "

"To educate people at a young age- primary school and secondary school about mental health and mental illness to help to reduce stigma. "

"...more community based services and services geared towards individuals needs."

"Old people need to be catered for more appropriately. "

"A legal support system within the hospital to give independent advice and information. To be treated with respect by professionals."

"More facilities for rehabilitation/recovery"

Conclusion

The title of this report, **"What we Heard"** reflects for those involved in carrying out this piece of work, the real voices of real people who otherwise do not get a chance to give their perspective on what it is like to experience severe distress and how the management and care of that distress is experienced.

For the members of the Irish Advocacy Network involved in this project, who themselves have had similar experiences of distress at one stage or another in their lives, the project provided an opportunity to engage in a process of lifelong learning which is one of the goals of Participatory Action Research (PAR). Specifically this has meant, for those involved, engagement by immersing oneself into the subjectivity of that which is being studied to draw out content which will in some way contribute to social change.

In this instance, this required courage, passion and commitment to the subject matter and for all involved this also requires an added dimension of revisiting and remembering some of our own painful experiences. The project team was very conscious of this component and built in structures to support and debrief members of the team which has added to the roundedness and robustness of the report.

It also needs to be stated that the aforementioned courage, passion and commitment was also evident in the decision taken by the Expert Group to commission this piece of work and reflected itself in the attitudes of staff at the various facilities visited.

"Every Society faces not merely a succession of probable futures but an array of possible futures and a conflict over preferable futures. The Management of Change is the struggle to convert certain possibilities into probables in the pursuit of agreed preferables"³.

³ A. Toffler. (1971) Future Shock Bodley Head. London.

Appendix 1

SECTION 1: PERSONAL DEMOGRAPHICS

1a Personal Detail:

- 1a i Gender Male: Female:
- 1a ii Age 18-25
26-35
36-45
46-55
56-65
66-75
75+

1b. Is your main place of residence?

- Rural Village Town Urban

1c. What is your main source of income?

- | | | | |
|---------------------------------|--------------------------|----------------------|--------------------------|
| Paid insurable employment | <input type="checkbox"/> | Supported employment | <input type="checkbox"/> |
| Rehabilitative work | <input type="checkbox"/> | Unemployment Benefit | <input type="checkbox"/> |
| Unemployment Assistance | <input type="checkbox"/> | Disability Benefit | <input type="checkbox"/> |
| Disability Allowance | <input type="checkbox"/> | Invalidity Pension | <input type="checkbox"/> |
| Supplementary Welfare Allowance | <input type="checkbox"/> | Contributory Pension | <input type="checkbox"/> |
| Non Contributory Pension | <input type="checkbox"/> | Other Pension | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | | |

1d. Educational Attainment

- | | | | |
|---------------------------|--------------------------|-------------------------------|--------------------------|
| Primary Level | <input type="checkbox"/> | Secondary level (Junior Cert) | <input type="checkbox"/> |
| Secondary level (Leaving) | <input type="checkbox"/> | Post Leaving Cert Courses | <input type="checkbox"/> |
| Third level certificate | <input type="checkbox"/> | Third level diploma | <input type="checkbox"/> |
| Third level graduate | <input type="checkbox"/> | Third level post graduate | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | | |

1e. Significant Relationship Status

- | | | |
|-----------------------|--------------------------|----------|
| Married | <input type="checkbox"/> | Single |
| Separated | <input type="checkbox"/> | Divorced |
| Same Sex Relationship | <input type="checkbox"/> | Other |

The county you live in:

SECTION 2: ADMITTANCE PROCEDURES

2a. Do you feel you admitted to hospital when you needed to be?

Yes: No:

2b. Were the physical surroundings in the admission/reception area comfortable and private?

Yes: No:

2c. Did you receive information on your rights under the Mental Treatment Act, 1945 and amending legislation, at the time of admission?

Yes: No:

2d. If no, did you receive information on your rights under the Mental Treatment Act, 1945 and amending legislation, within 24 hours after admission?

Yes: No:

2e. Did you understand the information on your rights under the Mental Treatment Act, 1945 and amending legislation.?

Yes: No:

2f. Were you introduced to the professional team responsible for your care.

Yes: No:

2g. Did you know who your treating consultant was?

Yes: No:

2h. Are Staff members identifiable?

Yes: No:

2i. Are staff available within a reasonable time?

Yes: No:

2j. Did you feel you have reasonable access to the consultant and members of the multi-disciplinary team?

Yes: No:

2k. Do you, your relatives and significant others have adequate privacy when being interviewed by staff

Yes: No:

2l. Do/did you feel you are treated with respect and dignity?

Yes: No:

SECTION 3: SERVICE SATISFACTION

3a. Did/ do you feel the service being provided is meeting your needs?

Yes: No:

3b. Have your recent experiences of mental health services been good or bad or mixed?

Good: Bad: Mixed:

3c. Can say more about what made your experiences good?

3d. Can you tell us more about what made your experiences bad?

SECTION 4: COMPLAINT PROCEDURES

4a. Are you aware as to how you can make complaints if dissatisfied?

Yes: No:

4b. Do you know what your personal rights are within the services?

Yes: No:

4c. Did any member of staff inform you of a procedure for complaints?

Yes: No:

4d. Were you aware of your rights in relation to refusal of treatment?

Yes: No:

4e. Would you complain if you felt aggrieved?

Yes: No:

4f. Was the environment of care restrictive?

Yes: No:

4g. Have you ever made a complaint?

Yes: No:

4h. If yes, what was the outcome?

4i. If you have made a complaint did you feel you got a fair hearing?

Yes: No:

SECTION 5: INFORMATION

5a. Were you given sufficient information as to what you were being treated for?

Yes: No:

5b. Were you given a diagnosis?

Yes: No:

5c. Were you aware of any care plan for you?

Yes: No:

5d. Has any information been provided to you about your medication, i.e. side-effects etc?

Yes: No:

5e. Was this information given to you verbally or in written form?

Verbal: Written: Both:

5f. Could you understand the information given to you about your treatment and medication?

Yes: No:

5g. Was a treatment plan discussed with you?

Yes: No:

5h. Do you feel you were given enough time to consider your treatment options?

Yes: No:

5i. Are you able to access your entitlements and benefits when you need them?

Yes: No:

5j. Do you have access to your own accommodation?

Yes: No:

5k. What medications are you currently taking?

1.	
2.	
3.	
4.	

Don't know

5l. Have you availed of ECT as a treatment?

Yes No:

5m. Did you give your full and informed written consent?

Yes: No:

SECTION 6. CHOICE

6a. Do you feel you have "CHOICE" within the services?

Yes:

No:

6b. If yes please state what?

If no what choices would you like to have available to you?

6c. Are you able to articulate your needs and wishes?

Yes:

No:

6d. If yes, what response do you feel you get?

If no, what would help you?

SECTION 7. ENVIRONMENT

What do you feel about the mental health facility you are currently using?

- | | | |
|--|------------------------------|-----------------------------|
| 7a. Clean | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7b. Good quality of food | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7c. Choice of menus | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7d. Portion size | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7e. Are your meals provided
at socially acceptable times? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7f. Friendly atmosphere | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7g. Good recreational facilities | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7h. Accommodating to you views
and beliefs. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7i. Courteous staff | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7j. Variety of daytime activities. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7k. Choice of daytime activities | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7l. Private bathing facilities. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

- 7m. Single gender toilet facilities. Yes No
- 7n. Access to smoking and Non-smoking areas; Yes No
- 7o. Access to private outdoor space. Yes No
- 7p. Access to public telephone. Yes No
- 7q. Easy access to public transport, churches and shopping facilities. Yes No
- 7r. Facilities for leisure activities. Yes No
- 7s. Adequate facilities for visitors. Yes No
- 7t. Have you access to personal hygiene requirements, i.e. razors, deodorant, sanitary towels etc Yes No
- 7u. Do you have a place to secure your personal belongings. Yes No
- 7v. Do you take charge of your own income? Yes: No:
- 7w. If no, is it managed by a member of staff or family? Staff: Family:
- 7x. Are you satisfied with this arrangement? Yes: No:

SECTION 8: GENERAL

8a.

What changes would have the greatest benefit for people's mental health and well-being, in your opinion? (please start with what you think is the most important change and if possible give five changes in order of preference)

Change 1

Change 2

Change 3

Change 4

Change 5

8b.

If extra money was to be invested in mental health, what in your opinion should the priorities be for spending that money?

8c.

Have you any other views or proposals for the new Mental Health Policy?

Appendix 2

EXPERT GROUP SERVICE USERS CONSULTATION

Safety of respondents is paramount, and should infuse all decisions

Safety Considerations	Recommended Measures to be taken
Ability of patient to conduct the interview	Exclude those too ill to take part (as guided by Clinician).
Informed Consent	Irish Advocacy Network to inform patient /carer of the consultation. Process to be explained and consent to take part in the interview before commencement of the interview.
Privacy, Confidentiality and Anonymity	Interviewer and respondent only to be present at the interview. No actual names to be used in transcription – if name is helpful use pseudonym. Any information that could identify an individual respondent should be aggregated and presented in such a way that such identification is not possible Interviewers should not carry out interviews in their own locality.
Voluntary participation and freedom to withdraw	Ensure patient does not feel any pressure to take part. Assure patient that while their participation is welcome, it is totally voluntary as part of the briefing session.
Consideration of effects of illness, tiredness.	Inform patient that it is ok to terminate the interview if they feel any effects such as tiredness etc.
Training and competency of fieldworker who carry out the interviews should be adequate for the purposes of the research.	Fieldworkers trained. Previous experience in consultation process with other Health Boards.
Provide for reduction of any possible concerns raised to the participants by the research	Incident Form to be completed Follow-up to offer support.
Ensure findings are properly interpreted and used to advance mental health review.	Ensure consultation follows procedures, and that appropriate dissemination of the results follows.
Sensitivity and appropriateness of questions asked	Use pre-tested/previously used interview schedule.

