

Recovery
Choice
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TALKING ABOUT CHOICE

Developing the dialogue for individual recovery and partnership



Schizophrenia Ireland Lucia Foundation

Schizophrenia Ireland is the national organisation dedicated to upholding the rights and addressing the needs of all those affected by enduring mental illness including, but not exclusively, schizophrenia, schizo-affective disorder and bi-polar disorder, through the promotion and provision of high-quality services and working to ensure the continual enhancement of the quality of life of the people it serves.

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FOREWORD



In 2002, Schizophrenia Ireland published its first survey of service users' experiences of medication and treatment entitled 'A Question of Choice – Ireland'. That document reported on the experiences of people receiving outpatient treatment. The survey aimed to gather information on important issues such as the type of medication prescribed, dosages, polypharmacy, side effects and the range of medications being used. The results gave us first hand information from the people most affected by treatment regimes, the service user. There were many issues which emerged from that research. Most significantly was the continual lack of quality information being given to service users, the issue of multiple drug prescribing and the paucity of alternative non medication based interventions. It was clear from the research results, that all too often the opinions of the service user and his/her family carers were not valued sufficiently in treatment appraisals.

'Talking about Choice' is Schizophrenia Ireland's second survey of service users' experience. This piece of research, conducted on behalf of Schizophrenia Ireland by University College Dublin, Centre of Disability Studies, builds on the 2002 research. 'Talking about Choice' enquires about the type of services received by individuals and the quality of those services.

Specific areas on which the research focused included:

- Which professionals were involved in delivering services to service users
- The nature of the relationship between the professionals involved and service users
- The quality of information exchanged between service users and professionals

Specific issues enquired about included the degree of compliance with medication regimes and the availability and range of alternative treatments. The enquiry also focused on the personal and social resources of the service user himself and how these affected the quality of the interventions. The findings of 'Talking about Choice' can be compared to the findings in 'A Question of Choice – Ireland' and it is clear from the analysis of both results, that many of the issues for service users apparent in 2002, still exist in 2006 i.e. the poor quality of information giving between service provider and service user, the issue of medication compliance and the paucity of treatments other than medication to assist recovery.

On a positive note, the survey findings suggest that mental health service users are now in a different climate. The research is published in the same year as 'A Vision for Change', a new Government policy for provision of mental healthcare services over the next ten years. 'A Vision for Change' highlights the need for significant changes including the need to focus on recovery, the need to have a more participative relationship between mental healthcare service providers and service users and the need to have access to additional professional support. These are significant issues, which were highlighted in the outcomes of our research. Schizophrenia Ireland hopes that the publication of 'Talking about Choice' will add to the debate about the need to provide an improved range of services for people experiencing mental health difficulties. Such services should be focused on the service user as the central character, and should be orientated towards assisting the individual to achieve the maximum degree of recovery possible.

John Saunders, Director, Schizophrenia Ireland



INTRODUCTION AND DISCUSSION

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Recently, an expert group assembled by the Department of Health and Children and comprising a valuable mix of service providers, service users and professionals has made a fresh attempt to create a climate for change by publishing its new policy document “A Vision for Change” earlier this year (Department of Health & Children, 2006). The framework for required changes, which this report envisions, is clearly expressed. Innovation is required in how we as a society promote and maintain good mental health, and also in the way we deliver our mental health services to those who require them. In considering the reported results of our research, we will fit them around the framework given to us in the “A Vision for Change” document.

The call for change and the framework that has evolved into the “A Vision for Change” document was developed through a process of consultation with service users and other stakeholders.

Among the most frequently cited themes for service provision and development in the document were:

- Active participation by service users in the process of recovery
- Recovery itself to be the focus of interventions
- Availability of a range of alternative treatments (e.g. talk therapies)
- Access to a range of professional expertise (e.g. multidisciplinary teams)

(Department of Health & Children, 2006, pg 13)

These themes argue for a more holistic approach to the treatment of people with mental health difficulties. Can our data point up any of the barriers that might exist to the achievement of such an approach?

Previous research consistently painted the service user as an outsider in the treatment process – uninvolved and so disempowered – particularly in relation to information sharing. This piece of research continues to reflect on a situation where service users of mental health services are not involved in a partnership with their mental health professionals.

WHICH PROFESSIONALS ARE INVOLVED?

To begin with, our respondents report high levels of contact with medical professionals like Consultant Psychiatrists and General Practitioners, yet low levels of contact with non-medical mental health professionals like Counsellors and Occupational Therapists (see Figure 3 across).

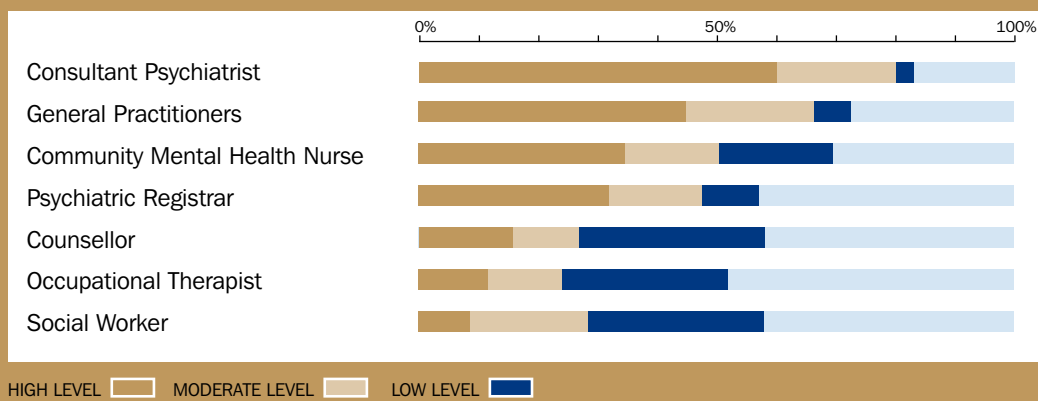
Why this might be, cannot be clarified by the data to hand. In other words we don't know if the non-medical professionals are in place and not referred to, or if they are simply not there because the posts are either not available or not filled. Whatever the explanation, the service user is somewhat limited in the range

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of professionals he can look to, and the vision of active multi-disciplinary teams will require that the issue of how non-medical expertise can be made accessible to all is addressed.

It is worth noting that in our results section titled '**Description of Mental Health Services**' there was a fairly high positive rating overall for the quality of service delivered (p3), but there are some concerns around their consistency with nearly 30% reporting dissatisfaction here. Qualitative data, not given by all participants, often indicated concerns over the way in which Psychiatric Registrars changed so often. While training needs of professionals are important and rotation of staff can beneficially broaden experience, there is a need for balance. If service users are to become active participants in their treatment, as is envisaged at policy level, then a pre-requisite is going to be consistency in whom they see and in what they are offered.

Figure 3
Levels of Contact with Different Mental Health Practitioners



Turning to specific quality ratings, that is, those relating to quality of relationship with mental health professionals and quality of treatment, the respondents are largely positive (74% and 69% respectively rate the quality as 'good' or 'very good'). **The qualitative data we have at hand helps us understand what people mean when they talk about positive quality of relationship – they say it involves a preparedness to listen, availability and professionalism.** This is something that has been heard back from service users before (Expert Group on Mental Health Policy, 2004). These comments from service users resonate with thinking that is already being articulated by some psychiatrists (see, for example, Bracken & Thomas 2001). It seems reasonable to suggest that these are the very qualities that need to be brought to bear in developing a partnership approach to treatment that empowers the service user to be an active participant. In a society where medicine is becoming ever more technological, it is important to highlight and value these qualities by giving them greater weighting in the training of medical professionals destined for the field of psychiatry.

There are small numbers who view both their relationship with their principal professional and their treatment negatively (7% and 8% respectively). While it might be argued that these low figures are 'acceptable', it is our intention to interrogate the data further in relation to these people and report on what we learn of how their experiences might have been negative at a later date.

We now turn to the data relating to which professional the service user sees the most in relation to his mental health difficulties. Of those who see a psychiatrist the most (Consultant or Registrar), more report a negative relationship and fewer report a positive relationship than those who see their GP or Community Psychiatric Nurse the most. This negative view of the psychiatrist may be





explained (though we cannot be certain from the data) by the fact that the psychiatric professionals are the ones the service user is most likely to see when he finds himself in extremis. In other words, psychiatrists are brought into the picture when situations are at their most difficult, making it easier for them to be perceived negatively. Such an explanation would support the argument, repeated and strengthened in “A Vision for Change”, that these professionals should be working closer to the communities they serve and that the psychiatric hospital should become a thing of the past (with the equity released by the sale of such facilities supporting a more diverse service). Such a move would enable psychiatrists to enter the treatment process at an earlier point – a move which would not only enable the reduction of the negative esteem in which they may be held, but would also add potency to interventions at primary care level by the presence of their expertise and specialist knowledge at that point.

Later in the questionnaire (see Table 7 below), we provided a list of characteristics that might be thought to be important in such a professional.

Table 7
Descriptive Statistics for Qualities Rating

Person seen	Range	Median	SD
Importance of trust	0-10.0	9.027	1.5856
Importance of competency	0-10.0	9.015	1.6720
Importance of listening	0-9.6	8.882	1.7325
Importance of explaining	0-10.0	8.759	1.7743
Importance of equality	0-9.7	8.459	2.2440

While the mean ratings reported are all high, indicating that each of these qualities is seen as important, it is the importance of ‘Trust’ that tops the list. When it comes to implementing the framework of ‘A Vision for Change’, it will be valuable to find ways of building an environment that fosters the development of such trust between service users and providers. The importance lies in the fact that trust will be crucial to active participation in the treatment process by the service user. It may also have an impact on the sometimes negative view in which psychiatrists have been shown to be held (see above).

WHAT DO PROFESSIONALS TALK ABOUT?

As we have already noted, respondents in this survey reported high levels of contact with medical professionals both in absolute terms and in comparison to contact with other professionals. We presented a range of issues, which were identified as important by our consultative committee, and asked respondents to comment on how frequently they were discussed. It may not be surprising, given that the professionals spoken to are by and large medical practitioners, but discussion of issues around medication is at the top of the list (see Table 5 across) while the subject of recovery is further down. This is worth noting if recovery is really going to be the focus of service provision in the future, as suggested by the ‘A Vision for Change’ document. Clearly there are implications for the education and training of medical professionals, which need to be addressed here.

There is room for further concern in relation to the development of a partnership approach to treatment, when we examine the data to see how medications are

discussed. 53% reported that they were given no choice in relation to medication. What does ‘choice’ mean? The qualitative data tells us that for the service user this relates to issues like having different medications on offer and being able to reduce the dosage of the medication that they are on. In a nutshell, it’s about being in control, as was succinctly stated by one respondent: **“I need to be in control more of the medication I take so I have something to say in what is happening to me, my body, my mind”**.

Perhaps to labour the point, the introduction of choice in this important area of treatment, promotes and ensures the active participation of the service user in the process. We will return to the issue of service user participation when we look at what respondents tell us about their compliance with prescribed medications.

Table 5
Frequency of Discussion of Issues

Area	High	Moderate	Low
Effectiveness of medication	45.8% (190)	31.6% (131)	14.7% (61)
Role of medication	32.3% (135)	28.9% (120)	23.6% (98)
Particular medication	31.8% (132)	33.5% (139)	24.1% (100)
Length of time on medication	31.4% (130)	19.5% (81)	36.1% (150)
Recovery	25.3% (105)	26.7% (111)	40.0% (166)
Side effects	16.0% (108)	32.8% (136)	30.4% (126)
Alternative medications	14.3% (59)	22.9% (95)	48.7% (202)

When speaking with professionals, 52% of service users said they had no choice in their treatment generally and the qualitative data showed that this related to issues like having access to non-medical interventions. Without choice, it is not surprising that some participants, nearly 20% of respondents, say they feel uninvolved in treatment. The qualitative data here mirrors that commented on above – service users want to be involved with non-medical approaches. But this is not to say they reject the use of medication, indeed a small percentage actively wish to continue on their present medication without change, while others express an interest in reducing dosage or trying other preparations.

As we have noted, discussion of recovery was lower down the list of topics discussed with doctors. What does talking about recovery mean? For those who answered the open-ended qualitative question, it may not mean recovery in the way we think about it in relation to physical disorders. Only 3% of those who chose to comment referred to it as being medication free, while 12% see it as continuing on medication, while the remaining gave a range of other responses. Clearly, if recovery is to be the focus of treatment, then some more work is needed in understanding what that means – not only to different groups of stakeholders (service users and providers particularly) but also to the individual service user.

MEDICATION COMPLIANCE

Medication is often seen as the cornerstone to treatment of mental health difficulties (near on 90% of the sample say they are taking medication at the time they respond to the questionnaire). Yet concerns are expressed, as they are in other areas of medical practice, around patient compliance. Can the data from the present study shed any light on this?



Of the sample, 44% reported that they had tried to stop their medication or at least reduce it at some point in their treatment. However, only 18% say that they were offered help in doing so. What this suggests is that a quarter of this group of service users modified or manipulated their treatment independently of those who were prescribing such treatment.

Here again we have evidence of a lack of partnership in the treatment process. The patient is not telling the doctor what is going on, but this may be in part due to the fact that neither is the doctor always telling the patient. The proportion of respondents who tell us medication issues are never discussed with them (see Table 5) is alarming. While a large number say alternative medications are never discussed with them (48%), the numbers of those who say they never have discussion around the medication they are actually taking at the time (24%) and its effectiveness (14%) are unacceptable.

This 'lack of discussion' is highly pertinent to the issue of compliance. **Returning to those who said they tried to stop or reduce medication, the most frequently given reason was 'side effects' of that very medication. But here again, the sample as a whole tells that for a substantial number (30%) the medical professional does not discuss this issue with them – even though nearly 86% report they have experienced such side effects.** One way to change this situation might be to introduce a modified version of the UK charity MIND's version of the Yellow Card Reporting System (Cobb, Darton & Juttla 2001). This facilitates service users in recording experiences with medications, and it could form the basis for discussion with the treating medical professional when a review appointment is taken up.

We know that nearly two thirds (64%) of those who came off their medication reported an overall negative outcome, so it is not difficult to appreciate that medication has some value for people with mental health difficulties. Perhaps it would help if there was more discussion of the positives and negatives of this. When presented with a range of medication side effects (see Table 9 below), never less than a quarter and sometimes more than half of the respondents said they had experienced the side effect. Around 28% say that side effects have a high impact on their day-to-day life, so one can understand the service user's motivation to modify medication intake. **In relation to the high reported levels of loss of energy and poor concentration, it seems clear that side effects could actually hinder return to, or continuation of, a 'normal' life style and thus become an effect rather than a 'side effect'.**

Table 9
Occurrence of Side Effects

Side Effect	Occurrence	Side Effect	Occurrence
Loss of energy	61.2% (254)	Shaking/tremors	33.5% (139)
Weight gain	57.8% (240)	Effects on eyes	30.4% (126)
Poor concentration	49.2% (204)	Sexual side effects	24.6% (102)
Dry mouth	45.8% (190)	Muscle spasms	24.3% (101)
Inner restlessness	43.9% (182)		

'A Vision for Change' reminds us of the importance of language in how we talk about issues around mental health. The use of the term '**side effects**' in relation to medication and service user compliance is a case in point. The observer who understands the main action of a preparation can

view the list of effects given in Table 9 as '**side effects**'. But for the service user they are more likely to be seen as 'effects'. Though we have no evidence for

saying this from our data, such effects could come to be seen by the service user as part of the illness rather than part of the treatment.

In any event, we should consider a change in labelling here, as it may help our thinking around the impact of these experiences. At the end of the questionnaire, participants were asked to identify the factors that had affected their quality of life – of the negative ones identified, ‘side effects’ was the most frequently mentioned. Perhaps not surprisingly, when service users are asked why they no longer experience side effects, the most frequent explanation they give is changing or stopping the medication.

Given the cost of psychiatric medication, and the above findings, it will likely be found that ‘it pays to talk’.



ALTERNATIVE TREATMENTS

Talking is something that comes quite high up the list when the respondents were asked to consider alternative forms of treatment. We asked questions around what had been offered and what had been tried in this area of intervention, and we found that when something was offered, generally speaking quite a high percentage took up that offer.

The highest uptakes were in relation to Group and to Peer Support. These options were offered to fewer people than were options like Relaxation and Art or Music Therapy, as a ranking of the percentages in Table 11 (see below) will show, but around 80% of those offered it take up the opportunity to talk.

Table 11
Use of Alternative Treatments

Side Effect	Offered*	Tried when Offered**	Offered but Not Tried**
Relaxation	46.3% (192)	78.1% (150)	4.7% (9)
Art, music therapy	38.8% (161)	78.2% (126)	6.2% (10)
Group therapy	37.6% (156)	84.6% (132)	1.3% (2)
Counselling	35.2% (146)	76.7% (112)	4.1% (6)
Exercise	28.2% (117)	76.9% (90)	4.3% (5)
Peer group support	25.3% (105)	79.0% (83)	3.8% (4)
ECT	22.4% (93)	76.3% (71)	9.5% (6)
Nutritional/dietary approach	18.6% (77)	77.9% (60)	7.8% (6)
CBT	15.9% (66)	75.8% (50)	13.6% (9)
Homeopathy	5.5% (23)	65.2% (15)	21.7% (5)

* Calculated as a percentage of the total group ** Calculated as a percentage of the group who were offered the treatment.

The numbers of people who try alternative treatments independently of any recommendation or advice (see Table 12 next page) are considerably smaller – a fact that reinforces the notion that it pays to talk or communicate. It does pay, because when they are asked to rate how helpful the recommendations of alternative interventions have been (see Table 13 next page), we find



consistently more than two thirds of the respondents report each intervention as helpful or very helpful. The one exception being ECT, though it should be noted that half of those who did accept ECT evaluated it as helpful/very helpful.

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Table 12
Independent Use of Alternative Treatments

Treatment	Tried Independently*
Homeopathy	3.9% (16)
Counselling	3.4% (14)
Peer group support	3.4% (14)
Relaxation	3.4% (14)
Exercise	3.2% (13)
Nutritional/dietary approach	2.9% (12)
Group therapy	2.7% (11)
Art, music therapy	2.4% (10)
ECT	0.5% (2)

* Calculated as a percentage of the total group

Table 13
Ratings of Helpfulness of Other Approaches

Approach*	Very helpful/ helpful*	Neither	Unhelpful Very unhelpful
Exercise	88.2% (98)	6.3% (7)	5.4% (6)
Peer group support	83.8% (83)	6.1% (6)	10.1% (10)
Nutritional/dietary approach	79.5% (62)	11.5% (9)	9.0% (7)
Art, music therapy	77.5% (110)	14.8% (21)	7.7% (11)
Counselling	76.9% (100)	11.6% (15)	11.5% (5)
Relaxation	73.6% (126)	13.5% (23)	12.8% (22)
Group therapy	71.8% (107)	18.1% (27)	10.1% (15)
CBT	70.0% (42)	13.3% (8)	16.6% (10)
Homeopathy	66.7% (24)	11.1% (4)	22.3% (8)
ECT	49.2% (34)	20.0% (13)	30.8% (20)

* These figures are reported as a percentage of those who tried the method and answered the question on helpfulness and therefore may differ from the previous table.

While exercise attracts the highest percentage of ratings at the 'helpful' end of the scale by the participants, Peer Support Groups comes in second. In terms of future planning, the place of Peer Support in the minds and experiences of service users is important to note. Earlier studies (e.g. Farrelly, 2002) have noted the reported usefulness of talk therapies, but Peer Support is different

from traditional Counselling or Group Therapy. It is a service user-to-service user approach and it promotes all the ideas that 'A Vision for Change' advocates, but

it lacks resources and is poorly funded. This may be why it comes sixth in frequency of being offered – it isn't widely available and where it is, professionals may not be aware of its presence or of its potential beneficial impact (we label the impact 'beneficial' in light of the ratings of helpfulness made by those who did have access to it). While government funding has been made available for training and development for this form of intervention or support, more could usefully be done in the knowledge that it will aid the realization of the developing framework of mental health services in this country. Supporting this notion is the most recent policy paper to come from the Sainsbury Centre for Mental Health (2006), which highlights, among other things, the need for government funding to: **“ensure there is investment in developing and sustaining networks of people who use services and their carers at local level”** (Sainsbury Centre for Mental Health, 2006, pg16).

In this section, we have focused on the helpfulness of alternative interventions offered and tried. It should be noted that over a quarter of the respondents (26.3%) did not report any alternatives being offered to them.

RESOURCES OF THE SERVICE USER

In any debate around service provision, available resources will be a central issue – whether it is funding to provide staff and the places from which they will work, or whether it is for training to develop and improve skills. In such debates, no consideration is usually given to the resources of the person or group for whom the service is being provided. In relation to those who use mental health services in the environment that is emerging in Ireland, it seems crucial that this issue be high on the agenda – how else can we ensure that service users become active participants in their own treatment?

We have already noted that when we approached some services to access their service users, we were advised that there would be difficulties in the ability of many of those service users to comprehend and respond to our questions. This would be before we ever asked such service users (as we did in the open-ended qualitative items) to express an opinion of their own. Of those who did take part in this study, it is true that 30% had experienced some third level education. But fully 10% had progressed no further in the system than primary school, and one can only speculate as to ability levels in dealing with issues around treatment of troublesome symptoms in situations that are often upsetting and distressful.

The fact that 47% of respondents say they have experience of Adult Education inputs suggests a desire for learning or knowledge, even when it may not have been readily accessible earlier in life. In a similar vein, of those **who took up our offer to say what choices they wanted in their treatment, 10% replied “Don't Know” suggesting a desire for choice, but no knowledge of the possibilities.**

We've already reviewed what our respondents have to say about discussion and information sharing with their medical professionals. We also learn that 10% don't know the name of their consultant. There is a range of possible explanations for this, but the overall impression to be gained is of a substantial proportion of service users who lack knowledge and information (knowledge being the framework within which one can evaluate and deal with information).

Educational inputs for people who become service users would not only support government policy around life long learning but would empower service users who may be disadvantaged in the service provision system by their lack of both knowledge and information. Peer Support organisations can provide such input, if adequately funded, and ready, support would be available for the accreditation of such training from the Adult Education and associated educational units and institutions in Irish third level education.



RECOMMENDATIONS

Having reviewed the responses to our survey, there are a number of areas where it is possible to inform evolving policy as articulated by “A Vision for Change”. The authors are acutely aware that more questioning and discussion are needed before such a list is developed. We therefore conclude our report with a list of needs, which can be viewed as items for further discussion and refinement.

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We identify:

- The Need for Access to Professional Support. Service users attach importance to the availability of the medical practitioner who is working with them for recovery. We know that someone who will listen and with whom trust can be developed is highly valued. We also know that other professionals working in the mental health field are not currently as accessible as they might be. This is either because they are not referred to, or because they are simply not available.
- The Need to Define What “**Recovery**” Means. There is a need to clearly articulate what “**Recovery**” means in the life of each service user. Our results show it will likely be different things to different people. The importance of arriving at a definition is that, if Recovery is to be the goal of treatment (as it should be), then it needs to be an agreed one. However, Recovery must not be confused with Cure. Being “**cured**” implies a category into which people can be slotted. Those who are not so classified may be deemed failures because they have not achieved some pre-set standard or expectation. “**Recovery**” is not so much about externally imposed expectations as about a journey to be taken. A journey that may at times stop, go back, inch forward or take an entirely new direction – but all the time a journey that has the traveller as its prime focus. A useful starting point for developing an understanding of Recovery is the Mental Health Foundation Report of service user-led research into people’s strategies for living with mental distress (Faulkner, A. & Layzell, S., 2000). In December 2005, the Mental Health Commission produced the discussion paper, A Vision for a Recovery Model in Irish Mental Health Services. This document provides an extensive overview of recovery, signifying an important initial step in exploring the definition of recovery within an Irish context. The issues highlighted in the Mental Health Commission report and in this document need to be translated into service provision. The policy document, ‘A Vision for Change’ also reflects the need to have a strong emphasis on recovery in all aspects of service provision.
- The Need to Develop Appropriate Language. This should be a language that reflects the experiences of service users rather than one that is imposed. As we have seen in our discussion of side effects, it may be that those things which are seen as subsidiary by one person in the treatment process may in fact be central to the experience of another person. This notion has already been appreciated by some medical professionals working at primary care level (see, for example, Lester & Gask, 2006)
- The Need to Develop (and Accredite) Educational Opportunities for service users. These are inputs that will appropriately develop service user understanding of their experiences and give them a foundation of information as well as information acquisition skills that will enable them to indeed become active participants in their treatment and recovery. In the survey conducted by the Irish Advocacy Network (Expert Group on Mental Health Policy, 2004a), education was a change that was spoken about in a number of ways. It was clear that respondents see the need for access to second chance education opportunities. “**Classes – English etc., computers....self-esteem and confidence....we should get another chance at education when we are well.**” (p32-33) were some of the comments made.

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CONTEXT FOR 'TALKING ABOUT CHOICE'

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IRISH HEALTH POLICY

Historically, the mentally ill of Ireland were housed in large psychiatric hospitals - the buildings of which, in many cases, started life as Workhouses or Poorhouses (Robbins 1986). In the latter part of the twentieth century, great hopes for improvement were raised with the publication of "Planning for the Future" (Department of Health, 1984), which suggested changes to the way in which services were delivered, as well as the hope of legislative reform

However, the possibilities laid out in the 1984 document lay largely unimplemented and, in the following ten years a slow move toward legislative reform was signalled with the publication of a Green Paper on Mental Health (Department of Health, 1992). This culminated in the Mental Health Act 2001 (Department of Health & Children, 2001a), which, at the time of writing, has not been fully implemented. This Act, the first piece of Irish mental health legislation in over 55 years, has drawn criticism from a variety of quarters. Most notable among these being Amnesty International, whose report "The Neglected Quarter" (Crowley, 2003) expressed concern at the failure to lay down standards of treatment or care and procedures for monitoring such standards in the legislation. In fairness, it should be said that the Mental Health Act 2001 has created a Mental Health Commission and, since its inception; the Commission has published its first Strategic Plan. Among its initial priorities, the Commission intends: "To provide and implement best standards of care within the mental health services" (Mental Health Commission, 2004).

The Commission has also appointed an Inspector of Mental Health Services to replace the Inspector of Mental Hospitals, thereby enabling the entire spectrum of what the state offers to people with mental health difficulties to be evaluated. This must be viewed as a positive development. However, it is important to ensure that any recommendations made by the new Inspector be both heeded and acted upon – one of the criticisms of the process under the previous Inspectorate being that many valuable directions for service amelioration were ignored.

As we prepare for new policy to become practice and for enacted legislation to be implemented, we are fortunate, here in Ireland, to possess a growing body of research that articulates the needs and concerns of service users in the mental health field. We now summarise some of that data. We do so with the caveat that this is not the end of a listening process – as some may wish - but rather the beginning of what could and should be a fruitful dialogue to enhance the efficacy of such services for the benefit of the entire community.

Simply put, we are still in the early stages of consultation with service users. This is a process that must continue to grow.

Most recently, the Department of Health & Children (2006) have published "A Vision for Change: Report of the Expert Group on Mental Health Policy". This has been developed after extensive enquiry and consultation with service users (Expert Group on Mental Health Policy, 2004a) and other interested parties (Expert Group on Mental Health Policy, 2004b) and it sets out a comprehensive policy framework for Irish mental health services over the next decade.



RECENT IRISH STUDIES

Recent years have seen a regular flow of research reports on how Irish service users experience the mental health services offered to them. Time and again, these research results suggest that the service user is an outsider in the process, deprived of both information about what is happening, and of involvement in working toward decisions as to how to move forward with the delivery of ameliorative treatment.

A QUESTION OF CHOICE

Schizophrenia Ireland carried out a questionnaire survey of mental health service users in the early years of the new Millennium (Farrelly, 2002). **This was a replication of a similar survey carried out by the National Schizophrenia Fellowship in the UK four years earlier (Hogman & Sandamas, 2000). Both the findings reported and recommendations made in the Irish study echo those of the UK survey.** The Irish questionnaire, which was distributed throughout the country by the various networks available to Schizophrenia Ireland, were completed anonymously and returned in reply-paid envelopes. 471 questionnaires were analysed, and the results revealed a troubling number of service users who were not being given access to information about their medical treatment or being enabled to access relevant alternative treatments.

With regard to the issue of 'information giving':

- 61% were not offered any choice in medication prescribed
- 66% said their doctor did not give them any written information on the side effects of their medication
- 42% were not given a written record of their medication and when to take it and, perhaps of most concern, even though it is the lowest figure in this data set
- 33% reported that their doctor did not talk to them about their medication at all

The author goes on to offer two recommendations from these findings:

- Written information on medications and treatment should be given to clients to facilitate informed decision making
- Information should be available in a format, which facilitates client understanding (pg 8)

As can be seen below, these recommendations, made by Farrelly (2002) repeat, almost word for word, the "Guidelines on Good Practice & Quality Assurance in Mental Health Services" laid down by the Inspector of Mental Hospitals four years earlier (Department of Health and Children, 1998):

- Written information should be available to patients on prescribed medication relating to its effects and side effects
- The nature of treatment and medication should be explained to patients in language they understand (pg 18)

These guidelines were written for service providers but, in light of the 2002 report from Schizophrenia Ireland, they have not had the impact that might be wished for. As already noted, there have been concerns expressed about how much notice has been (and will in the future) taken of people who are put in place as watchdogs for an often less articulate and certainly less empowered section of our community.

Having noted the findings reported by Farrelly, Timms, Guerin, & O'Farrell (2004) they performed further analysis of this data, they reported their results to the National Disability Authority, noting that while there were valid concerns about the numbers of people not receiving information about their treatment, the picture for women and older people was even worse. There were significant differences between men and women and between younger people and older people in terms of the information they were given, and these differences were consistently in favour of the former group in each case. The authors drew attention to the fact that the disadvantaged groups in each case (women and older people) were covered for equality of access to services by the Equal Status Act 2000. However, clauses in that Act exclude issues relating to medical treatment, and so these inequalities in access to information will be allowed to continue – with such service users having no access to redress.

And, it goes without saying, that there is no redress for the entire service using population under discussion here when, four years after they were published, research by Schizophrenia Ireland clearly indicated that the Guidelines on Good Practice in relation to an important aspect of service delivery were not being complied with. This highlights the need for not only the laying down of standards in this area, but also for the monitoring of same – which both Government Health Strategies and the Mental Health Commission seem to promise.

With regard to the availability of non-medical interventions, the Schizophrenia Ireland study noted the on-going debate about the efficacy of such treatments, but suggested **“the best way to establish efficacy is to ask the people who experience a particular treatment”** (Farrelly, 2002, pg 6). When this was done, it was found that only 56% of respondents had experienced counselling, yet within the fortunate 56% of service users, 82% were able to report that counselling was helpful or very helpful to them.

A further anomaly to the studies reported by Timms, Guerin and O'Farrell (2004) was recorded here. When the access to counselling figures were broken down on a regional basis, it was found that 67% of respondents in the old ERHA catchment area had received counselling, while the figure for the rest of the country was 48%. This is another example of imbalance in the way that mental health services are delivered – and another cause for concern to those who argue for standards in service delivery.

THE PATHWAYS REPORTS

The Pathways Report (Brosnan et al, 2002) was compiled of interviews with 51 people who had been involved with mental health services in the Galway city area between June and December 2000. The overall picture painted by this study shows that people were slow to present to services when they realised they were in difficulty. **“55% of those surveyed said that they were ill for more than a year before contacting the mental health service, and 30% were ill for more than five years”** (pg 43). The usual administrative response to such information is to demand some community wide intervention (such as awareness promotion within the educational system) in order to change attitudes, de-stigmatise emotional difficulties and promote early referral for help. This may well be helpful: the authors report that 59% of their respondents were fearful of approaching the psychiatric service. The fears of this 59% did indeed relate to stigma – but included fears of the possibility of being locked up, the sort of treatment they might be given, and attack by other patients as well.



What is of real concern here is that for 42% of the sample, such fears were not allayed by the experience of hospitalisation – they could not report that their first contact with services was “reassuring”. This suggests that no amount of awareness raising in schools or anywhere else is going to alter the situation.

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The concerns, and indeed the fears, of people prior to presenting themselves for treatment at a psychiatric hospital seem to be justified by some of the subsequent experiences reported by this sample when they are hospitalised. For instance:

- 71% said their illness was not discussed adequately with them
- 67% reported their testament programme was not discussed adequately with them
- 82% said they were not involved in planning their own treatment
- 73% said they'd like more information on their diagnosis
- 84% reported no involvement in planning their own activity programme while in hospital
- 52% said they had not been involved in decisions about their discharge from hospital
- 41% had a crisis after-hours, and felt this could have been dealt with more effectively

Such figures indicate a lack of partnership between service providers and service users, and a consequent lack of ability to participate in what is happening to them by a substantial number of service users. It is perhaps obvious, but important, to record that such ‘lack of ability’ has less to do with the capacity of the service user to comprehend and more to do with the ability of the service provider to actually provide. The failure to include the service user as an agent of her/his own change through the provision of information and a partnership that demonstrates parity of esteem must have serious consequences for the achievement of such change.

Psychology offers us a rich literature on locus of control and how, in the realm of health care, ensuring that such locus resides in the patient or service user and is not left to “chance”, “fate”, or a “powerful other” – as the alternatives are labelled – leads to enhanced outcomes for the individual. Figures reported in a recent review of the activities of Irish psychiatric services (Daly et al, 2004) tell us that 71% of all admissions for psychiatric help are re-admissions – and one can only speculate as to how far these re-admissions might have been reduced by closer working with those patients who report exclusion from their own process.

The figures reported above from the Pathways Report (Brosnan et al, 2002) tell us that the intervention that is needed (and which should, incidentally, be cheaply available) is not so much the engineering of community awareness (though this is important) but the reform of how mental health services meet and work with those who seek their help. As the report itself states: **“In essence, both the problems and the solutions are based on communication between service users and service providers”** (Brosnan et al, 2002, pg 23).

Another service user led piece of research was conducted in East Galway and led to the East Galway Pathways Report (Wynne et al, 2004). This study involved the interview of 34 service users between June and December 2002, and asked broadly similar questions to those asked in the Galway city study. While enquiries were sometime phrased differently (e.g. the East Galway researchers asked their respondents if their illness was discussed with them, while

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the Galway city study wanted to know if it was adequately discussed), and the East Galway study often reported higher levels of information giving, discussion and therefore partnership for its respondents – the concern nevertheless remains that a significant proportion of services users surveyed in both studies are not being properly involved in the process of dealing with their mental health concerns.



THE VIEWS OF SERVICE USERS – RESEARCH REPORT

“The Views of Service Users – Research Report” is another service user-led piece of research that “does what it says on the tin” (Making Minds Matter, 2004). The respondents were largely from the Dublin area (63%), and the findings reflect what the earlier studies cited above have reported.

In relation to communication of information, the authors noted: **“There were concerns with how a diagnosis was conveyed, which was often in a style which inferred there was no hope, although little information on prognosis was ever given”** (p12) – a comment which reinforces the impression from the earlier studies of a reluctance to inform and work in partnership on the part of some providers.

A further comment: **“Complaints about aspects of treatment, for example, aren’t heeded because of your diagnosis. Mental Health Professionals and family don’t trust your opinions or interpretations any more and you start to doubt them yourself.”** It was this experience...which explained why some respondents were so keen on giving up medication and moving away from their diagnosis and the label of mental illness, that gives us an insight into the issue of **“patient compliance”**, eloquently debunking the myth that such behaviour can be simply dismissed as the **“intransigence of a nutter”**.

ATTITUDES TO MENTAL ILLNESS SURVEY

The Mental Health Association conducted research from another perspective (Mental Health Ireland, 2003). They commissioned a survey of the general public in relation to issues relating to mental illness. While the findings are not central to the debate on particular issues around service provision, they do suggest a climate in the wider community that supports the changes that service users themselves are looking for.

Of the 1000 people surveyed, 98% agreed that we as a society **“have a responsibility to provide the best possible care for people with mental illness”** – a finding which is further supported by the 95% who feel any increase in spending on mental health services would not be a waste of money.

91% would say that, **“as far as possible, mental health services should be provided through community based facilities”**. This view of the general public is in line with policy recommendations that have been made down the years since the publication of “Planning for the Future” (Department of Health, 1984) – recommendations, which have yet to be properly implemented.

Again, the respondents are consistent in their own opinion: 89% of them going on to agree that **“the best therapy for many people with mental illness is to be a part of a normal community”**. And the fact that 80% of the sample disagree that **“people with mental illness should not be given any responsibility”** should help to motivate those policy makers who so far have only talked about partnership with service users and paid scant attention to the role of peer advocacy.



QUALITY IN MENTAL HEALTH – YOUR VIEWS

One of the first tasks taken on by the Mental Health Commission was to conduct a wide ranging consultation with stakeholders, which they published under the title “Quality in Mental Health – Your Views: Report on the Stakeholder Consultation on Quality in Mental Health Services” (Mental Health Commission, 2005). The stakeholders included service users, their family members and carers – and the consultation emphasised defining what constitutes a quality service in this area of delivery. Not surprisingly, perhaps, the results are in accord with and echo those reported above in the various service user-led studies.

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The report identifies thirteen themes around what constitutes quality in mental health services. Within these themes, the main facets identified include:

- Knowledge and information to support involvement
- Choice and a range of interventions
- Access to peer support
- Equitable access

The recommendations emerging from the report include the notion of empowering people who use mental health services. This is something that a few small groups have already done for themselves – as evidenced by the research reviewed above. However, it remains the case that these voices need to be heard more widely.

WHAT WE HEARD

This was a survey of service users (Expert Group on Mental Health Policy, 2004a) carried out by the Irish Advocacy Network over eight of the ten Health Boards in operation at that time. It involved interviews with 100 service users currently using acute or long-stay psychiatric facilities.

The report echoes many of the themes emerging in earlier research, and the findings are clearly reflected in the framework document that was to follow (“A Vision for Change”, Department of Health & Children, 2006). Here again, a significant minority (28%) were saying they did not receive information on the drug treatment they were being given, nor did they know what medication they were currently taking. Only 40% felt they had any choices with the services they were receiving at that time.

But perhaps the clearest message from this survey is the need – perhaps it should be a demand – to talk. Respondents articulate it in relation both to the staff they deal with: “doctors and nurses to take obligatory courses in people skills and in communication skills” (p29), and their own appreciation of a real need:

“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” (p31).

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THE WIDER PICTURE

It is important to realise that the issues thrown up by the service user-led research reviewed are not peculiar to Ireland. Similar studies have been undertaken throughout the UK and in Northern Ireland, and these echo and reflect what we have presented above. Examples are to be found in the research reports commissioned by the National Schizophrenia Fellowship (Hogman & Sandamas, 2000), the Mental Health Foundation (Faulkner, 1997), and the mental health charity MIND (Cobb, Darton & Juttla, 2001). These initiatives have encouraged the development of policy in which the Sainsbury Centre for Mental Health has been most active (see, for example: Sainsbury Centre for Mental Health, 2006).

It is heartening to see research that is service user-led or service user-influenced impacting on policy. For future research initiatives, given the comparability of findings in the above-mentioned studies, there is likely to be merit in developing projects that join interested parties in different jurisdictions, with a view to maximizing the impact of the important messages that are there to be heard.



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RESULTS

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RESPONSE RATES

Of the 3292 questionnaires distributed, 415 were completed and returned, representing a 12.6% response rate. The majority, 98.3% (N=408), were self-reports, 1.4% (n=6) were parent report and 1 (0.2%) was completed by a trainer. It should be noted that in the findings below percentages vary from 100% due to missing data.

DEMOGRAPHIC DETAILS

In addition to the demographic information reported in the method section, the educational level and employment status of the group was also examined. 10.6% (n=44) reported primary school as the highest level to date, 43.9% (n=182) had completed some level of secondary education, while 29.9% (n=124) had completed some third level education (including certificate, diploma, graduate or postgraduate qualification). 47.2% (n=196) also reported that they had completed some adult education. In examining employment status a number of categories were considered and these are reported in Table 2 below. The two most common categories were “unemployed” and “attending training centre”, with approximately one fifth of participants falling into each of these categories.

Table 2
Employment Status

Status	Percent	Frequency
Unemployed	22.7%	94
Attending training centre	20.7%	86
Part-time employment	14.5%	60
Full-time paid	11.6%	48
Sheltered employment	10.4%	43
Gov employment scheme	6.0%	25
Voluntary work	2.7%	11
Full-time student	2.2%	9
Retired	1.4%	6
Homemaker	0.5%	2
Self-employed	0.5%	2

Participants were asked to report the frequency of contact with their family, and over three-quarters (81.9%, n=336) described a high level of contact. However, 15.2% (n=63) reported moderate contact, while 2.7% (n=11) reported low levels of contact with their families. In reporting how supported the participants felt by their families, they were asked to indicate on a 10cm visual

analogue scale, where 10 represented very supported while 0 represented feeling not supported. The mean response was 7.71 (SD=2.92) suggesting a relatively positive sense of support.

DESCRIPTION OF MENTAL HEALTH SERVICES

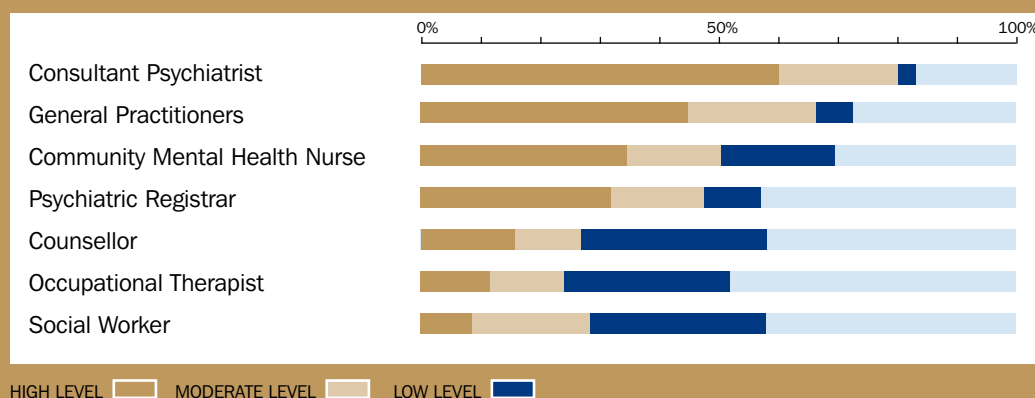


The majority of the participants reported that they were public patients (81.4%, n=338), while only 12.3% (n=51) reported that they were exclusively private patients. 1.7% (n=7) reported accessing both public and private services. Participants were also asked if they felt there was consistency in their contacts with professionals and 60.5% (n=251) responded positively. However 29.6% (n=123) reported that they did not experience consistency. Following this participants were asked to report how often they had contact with a number of mental health professionals. Table 3 and Figure 3 below report the breakdown of respondents, however it should be noted that there are high levels of missing data for some categories.

Table 3
Percentage (n) Reporting Different Levels of Contact

Professional	High	Moderate	Low
Consultant Psychiatrist	60.7% (252)	21.7% (90)	3.6% (15)
General Practitioners	46.5% (193)	20.5% (85)	6.3% (26)
Community Mental Health Nurse	33.5% (139)	17.1% (71)	19.5% (81)
Psychiatric Registrar	30.6% (127)	14.2% (59)	12.8% (53)
Counsellor	13.5% (56)	11.6% (48)	31.3% (130)
Occupational therapist	11.6% (48)	15.7% (65)	29.2% (121)
Social Worker	8.2% (34)	19.8% (82)	29.4% (122)

Figure 3
Levels of Contact with Different Mental Health Professionals



Almost three-quarters (73.7%, n=306) reported that they had received inpatient care at some point, while 64.3% (n=267) reported that they had received aftercare. Participants were asked to rate the quality of this treatment (using a visual analogue scale where 10 represented very good service, while 0 represented very poor service). The mean rating of quality of inpatient care was 6.83 (SD=3.14), while the mean score for aftercare was 6.56 (SD=3.44). These scores represent relatively positive ratings of services. In addition, 39% (n=162) reported that they had experienced involuntary detention, while a further four participants (1%) reported that while they had never formally experienced involuntary treatment, they perceived their treatment as such.



FREQUENCY AND NATURE OF CONTACT WITH MENTAL HEALTH PROFESSIONALS

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Participants were then asked to identify whom they saw most often in relation to their mental health difficulties and whom they talked with most in relation to their difficulties. Table 4 below reports their responses to these two questions. In addition, participants were asked to report how often they talked with the person they indicated below. Over half (55.9%, n=232) reported that they talked with them with high frequency, 29.2% (n=121) talked with them with moderate frequency, while 8% (n=33) reported a low frequency. Over three-quarters (76.9%, n=319) reported that they knew the name of their consultant, while interestingly 10.8% (n=45) did not.

Table 4
Professionals Seen and Talked with Most About Difficulties

Response	See most	Talk with most
Consultant Psychiatrist	39.8% (165)	41.9% (174)
Community Health Nurse	18.3% (76)	19.3% (80)
GP	16.9% (70)	14.5% (60)
Psychiatric Registrar	14.0% (58)	12.5% (52)

Following this, participants were asked to indicate how often a number of issues were discussed with them. Table 5 below reports the frequencies of response for each area of discussion. It is interesting to note that issues such as alternative medications and recovery are less frequently talked about.

Table 5
Frequency of Discussion of Issues

Area	High	Moderate	Low
Effectiveness of medication	45.8% (190)	31.6% (131)	14.7% (61)
Role of medication	32.3% (135)	28.9% (120)	23.6% (98)
Particular medication	31.8% (132)	33.5% (139)	24.1% (100)
Length of time on medication	31.4% (130)	19.5% (81)	36.1% (150)
Recovery	25.3% (105)	26.7% (111)	40.0% (166)
Side effects	16.0% (108)	32.8% (136)	30.4% (126)
Alternative medications	14.3% (59)	22.9% (95)	48.7% (202)

In an open-ended question participants were asked to describe their understanding of recovery. The most common response was that recovery involved continuing to take medication (12.3%, n=51) as seen in the following quote “**Tablets, until I have side effects then change or go off them, then back on them because I can’t live without them**”, while only 3.4% (n=14) felt recovery involved being free of medication (“**getting off all medication and leading a normal life**”) and 1.9% (n=8) saw recovery as continuing non-drug therapies. This theme is typified by the following quote, “**ongoing could talk to a good psychologist.**”

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Moving away from treatment related definitions, 12.3%, (n=51) defined recovery as being able to cope and have a full life. One participant reported **“recovery would be coping and live life”**, while another described recovery as **“the ability to lead a full and normal life.”** More specific responses included being symptom free (4.8%, n=20), **“If I recovered I wouldn’t have dreams and hallucinations and hear voices”**), being able to work (4.6%, n=19, **“to have a fulfilling job”**), and receiving support from others (2.7%, n=11, **“having supportive people in your life is essential if you are lucky having a supportive family”**). Finally, 3.8% (n=16) reported they did not expect to recover, for example one participant wrote, **“unless new medication comes on market I believe I will always have a problem”**, while another reported **“I was informed there is no recovery.”**

Participants were also asked some questions around choices. Over half of the group (53%, n=220) reported that they had never been offered choices around medication, 26% (n=108) were offered choices with moderate frequency, while only 12.3% (n=51) were offered choices with high frequency. Reports of choice in general treatment were similar with 52% (n=216) responding that they were never offered choices, 24.8% (n=103) responding moderately and 13.3% (n=55) reporting that they were offered choices with high frequency.

Participants were asked to comment qualitatively on the nature of choices they were offered. Their comments were analysed using content analyses and key themes were identified. Overall 13% (n=54) reported that they were offered choices in medication: **“different quantities lower amounts of medication”**, **“I was offered choices on trying out different types of medication”**. 5.1% (n=21) were offered choices of other formal therapies (including counselling, cognitive behavioural therapy and psychotherapy), while 4.1% (n=17) were offered other choices including a day care place, natural therapies and support groups.

The same procedure was used in examining comments around what choices participants reported they would like to be offered. A similar number 13.7% (n=57) reported that they would like choices in medication, (**“a review of my medication and not to be on unnecessary medication”**, **“I need to be in control more of the medication I take so I have something to say in what is happening to me, my body, my mind”**). In addition, 6.9% (n=29) would like choices of other formal therapies (including counselling, psychotherapy and cognitive behaviour therapy), while 6.9% (n=29) would like choices to include natural or herbal therapies. Interestingly 9.9% (n=41) responded **‘don’t know’** to this question, suggesting a desire for choice but a lack of knowledge about what might be possible.

Following this, participants were asked how involved they felt they were in their general treatment. 29.2% (n=121) responded **‘very involved’**, 34.9% (n=145) responded **‘involved’**, while 19.8% (n=82) responded **‘not very involved’** and 9.2% (n=38) responded **‘not at all involved’**. Participants were asked to qualitatively comment on their hopes for their future treatment or recovery plan.

Again content analysis identified a number of core themes (multiple responses were possible). One fifth (20%, n=83) reported they would like to be free of medication, with responses such as **“that my psychiatrist would at some time say that I no longer need the medication”**, **“I want to quit medication as soon as possible as they dull your emotions and your mind”** and **“the vision that I eventually will be discharged from the mental health clinic and that medication will be eliminated completely”**.

In addition, 3.6% (n=15) would like to reduce their medication (for example **“I would like to be on less medication”**) and 6% (n=25) reported they would like to continue on their current or new medication, with one participant hoping for **“discovery of a mood stabiliser which would suit my particular body chemistry.”** Interestingly 4.1% (n=17) reported they would like to access alternative treatments including counselling, psychology and **“a more holistic approach to treatment/recovery.”** Looking at other themes, 5.1% (n=21) reported they would like to get a job (**“to try and return to**



a work routine”), while 1.7% (n=7) expressed an interest in completing a course or training (“to retrain for part-time work”). Finally, 5.8% (n=24) reported they were happy as they were, with one saying, “[I] feel I am already recovered. As with any human being I now try to live a lifestyle that helps me protect/manage my mental health.”

Participants were asked to comment on the quality of their relationship with the person they dealt with most. Nearly three-quarters (74%, n=307) reported that their relationship with this person was positive, 12.8% (n=53) described it as neutral, while 6.6% (n=27) described the relationship negatively. The majority of the group felt that the person indicated had adequate knowledge of mental health (80%, n=332). An open-ended question asked participants to explain the quality of the relationship and content analysis identified a number of factors that influenced the perceptions.

The most common of these was the quality of communication (27.2%, n=113), with comments such as **“always listens to me and answers my questions”**, and **“the current doctor is only fair at communicating.”** A second factor was the personal qualities of the person (22.2%, n=92), as seen in the following quotes, **“He’s a very nice guy, very professional and I get on well with him”**, and **“I think she can be very patronising.”**

A more practical theme emerging from this analysis was the availability of the professionals (3.9%, n=16), with comments including **“He is available at both the best and worst of times”** and **“because you don’t see her often.”** A related theme concerned the impact of changes in staff and the impact on the relationship (6%, n=25), however unlike other themes the comments were mainly negative for example, **“registrars change every six months just as you are beginning to get used to them,”** and **“I see different registrars all the time so I don’t have time to build relationships.”**

A final theme was the influence of treatment on the relationship (3.9%, n=16) and this can be seen in the following quote, **“I am no longer on medication due to the progressive outlook of this person.”** Participants then rated the quality of their treatment and 69.1% (n=187) reported the treatment was positive. An additional 15.4% (n=64) described it as neutral, while 8% (n=33) described the quality of treatment negatively.

In order to further explore the issue of quality of interaction, the responses to this question were tabulated with whom the respondent sees most often in relation to their mental health difficulties. Table 6 below reports the findings.

Table 6

Cross Tabulation of Person Seen Most Often and Quality of Relationship

Person seen	Positive	Neutral	Negative
Community Mental Health Nurse	87.3% (62)	5.6% (4)	7% (5)
GP	82.1% (55)	13.4% (9)	4.5% (3)
Consultant Psychiatrist	77.2% (125)	14.8% (24)	8% (13)
Psychiatric Registrar	67.2% (37)	23.6% (13)	9.1% (5)

QUALITIES IDENTIFIED AS IMPORTANT IN A MENTAL HEALTH PROFESSIONAL

Aside from reporting the actual quality of the relationship with their key professional, participants also reported the importance of certain qualities in a good mental health professional. Table 7 below reports the mean, standard deviation and actual range of participants' scores. All items had a possible range of 0-10, with a high score indicating greater importance.

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Table 7
Descriptive Statistics for Qualities Rating

Person seen	Range	Median	SD
Importance of trust	0-10.0	9.027	1.5856
Importance of competency	0-10.0	9.015	1.6720
Importance of listening	0-9.6	8.882	1.7325
Importance of explaining	0-10.0	8.759	1.7743
Importance of equality	0-9.7	8.459	2.2440

KNOWLEDGE OF AND CONTACT WITH VOLUNTARY ORGANISATIONS

In order to explore this issue participants were asked to report if they had heard of, or had contact with a number of organisations. Table 8 below reports the responses across the group. Participants were also asked to rate the quality of the contact they had with these voluntary organisations. Overall 55% (n=191) described their contact positively, 14.9% (n=62) felt it was neutral, while 15% (n=62) rated the contact negatively.

Table 8
Contact with Voluntary Organisations

Organisation	Heard of	Contact with
Samaritans	54.9% (228)	16.6% (69)
AWARE	50.1% (208)	18.6% (77)
MHI	48.7% (202)	8.2% (34)
Schizophrenia Ireland	43.4% (180)	36.6% (152)
Grow	41.0% (170)	21.4% (89)
IAN	27.7% (115)	13.3% (55)



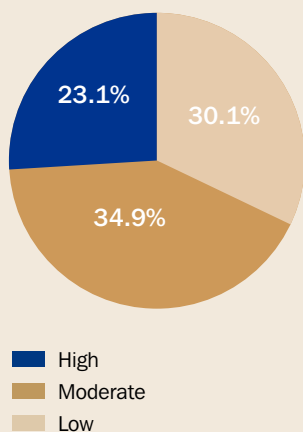
MEDICATION

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The next section of the questionnaire explored issues relating to medication. The majority of the group (89.4%, n=371) reported that they were currently taking medication. However, when asked what medication they were taking, 21.2% (n=88) did not answer, while another five (1%) responded ‘don’t know’ or ‘can’t remember’. The average number of medications participants reported taking was 2.6 (SD=1.7), and the range was one to nine. Of those who reported they were taking medication, 15.4% (n=57) were taking antipsychotics, 8.4% (n=31) were taking anti-depressants, 7% (n=26) were taking mood stabilisers, 8.4% (n=31) were taking night sedation, 3.8% (n=14) were taking anxiolytic medication, 2.2% (n=8), were taking anticholinergic medication and one participant was on alcohol control medication. However not all participants who reported they were taking medication reported what medication they were taking. In addition, whether the medication was typical or atypical was also recorded. 9.4% (n=39) were taking atypical medication, 2.9% (n=12) were taking typical medication, while 5.3% (n=22) were taking both. Only nine participants (2.4%) were receiving their medication as an injection.

One third of the group (33.3%, n=138) reported that they had tried to stop their medication in the past, while 18.6% (n=77) had tried to reduce their medication. Adjusting the figure to avoid double counting those who had done both, 44.1% (n=183) said yes to at least one of these questions. In an open-ended question participants were asked why they had come off or reduced medication. The most commonly reported reason was side effects (n=49, 22.8% of those who had stopped or reduced), with comments including “because it was making me too sleepy”, “dislike of side effects, uncomfortable taking medication” and “I found I was too drowsy and putting on weight too.” This was followed by the belief that the participant could do without them or did not need them (18.1%, n=39, “because I felt I was right not to take them and that they wouldn’t help”, “thought I could do without”). Other reasons given included thinking they were well (17.4%, n=24, “I thought I had fully recovered”, “I thought I was better”), and to be in control (3.6%, n=5, “didn’t want to be on any tablets, wanted to be in control”).

Figure 4: Frequency of Discussing Side Effects with Doctor



In reporting the outcome of coming off their medication, 32.6% (n=45) of those who had stopped reported a positive outcome, with comments including “I reduced the amount in Nov ‘03 and the anxiety had gone away and now I am fine” and “I ended up with better health”. However, 63.6% (n=88) reported a negative outcome, with comments including “[the decision] was disastrous – severe depression and difficulty returning to the psychiatrist”, “I reverted back to being sick within three months” and “I became unstable”. Interestingly 18.1% (n=75) of the overall group reported that their doctor had offered to help them come off their medication.

Participants were also asked to report how often their doctor had asked about experiencing side effects. Of the group 30.1% (n=125) reported low frequency, 34.9% (n=145) reported moderate frequency, while 23.1% (n=96) reported this happened with high frequency (see Figure 4 left).

Overall, 85.5% of the sample (n=355) had experienced side effects, either currently or in the past. In addition, participants were asked to identify what side effects they had experienced and to rate their severity. Responses are reported in Tables 9 and 10 across (see also Figure 5).

Table 9
Occurrence of Side Effects

Side Effect	Occurrence	Side Effect	Occurrence
Loss of energy	61.2% (254)	Shaking/tremors	33.5% (139)
Weight gain	57.8% (240)	Effects on eyes	30.4% (126)
Poor concentration	49.2% (204)	Sexual side effects	24.6% (102)
Dry mouth	45.8% (190)	Muscle spasms	24.3% (101)
Inner restlessness	43.9% (182)		

Figure 5
Frequency of Occurrence of Side Effects

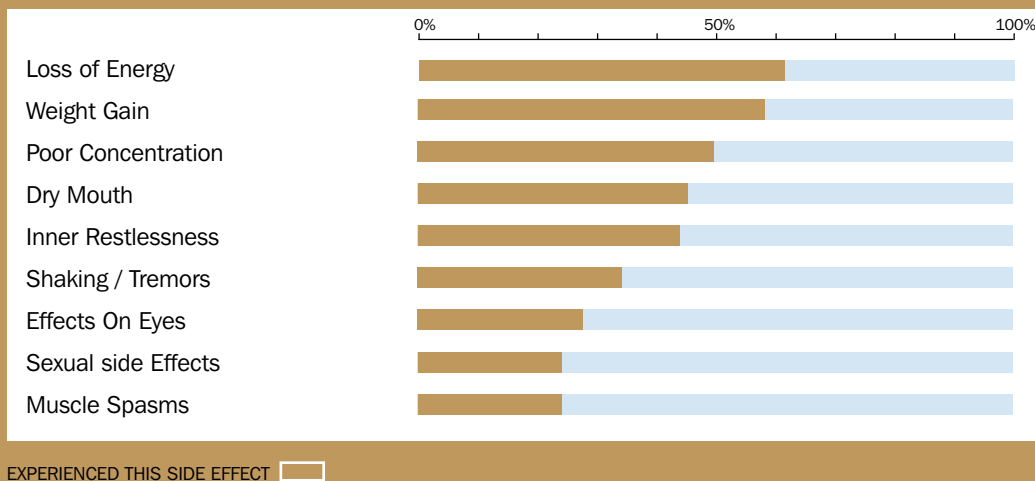
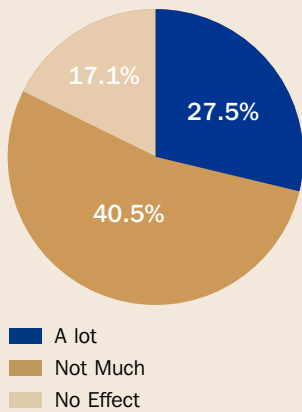


Table 10
Severity of Side Effects

Side Effect	Very bad	Bad	Tolerable
Sexual side effects	35.3% (36)	28.4% (29)	37.3% (38)
Inner restlessness	23.1% (42)	31.3% (57)	39.6% (72)
Poor concentration	22.5% (46)	29.4% (60)	33.3% (68)
Weight gain	22.1% (53)	29.6% (71)	35.8% (86)
Loss of energy	21.3% (54)	13.9% (81)	30.7% (78)
Dry mouth	20.5% (39)	30.0% (57)	37.9% (72)
Muscle spasms	17.8% (18)	31.7% (32)	51.5% (52)
Effects on eyes	15.1% (19)	33.3% (42)	42.9% (54)
Shaking/tremors	13.7% (19)	30.9% (43)	49.6% (69)



Figure 6: Reports of Impact of Side Effects



Participants then reported the impact these side effects had on their day-to-day life. Just over one-quarter (27.5%, n=114) reported they effected them 'a lot', 40.5% (n=169) responded 'not much', while another 17.1% (n=71) reported no effect on their everyday life (see Figure 6 left).

A qualitative question asked individuals to describe why they no longer experienced side effects and 21.7% (n=90) responded (multiple answers were possible). The most frequently reported reason was changing medication (42.2%, n=38), followed by stopping medication (22.2%, n=20). Other explanations given included getting used to the side effects (16.7%, n=15), changes to dosage (11.1%, n=10), receiving treatment for side effects (8.9%, n=8) and changing their lifestyle (7.8%, n=7).

NON-MEDICAL – ALTERNATIVE TREATMENTS

The final major section of the questionnaire explored participants' experience of non-medical or alternative treatment methods. Participants were asked to report if they had been offered any of a variety of alternatives, and if they had tried them. Table 11 below reports the frequencies of being offered and usage of each alternative (see also Figure 7 across).

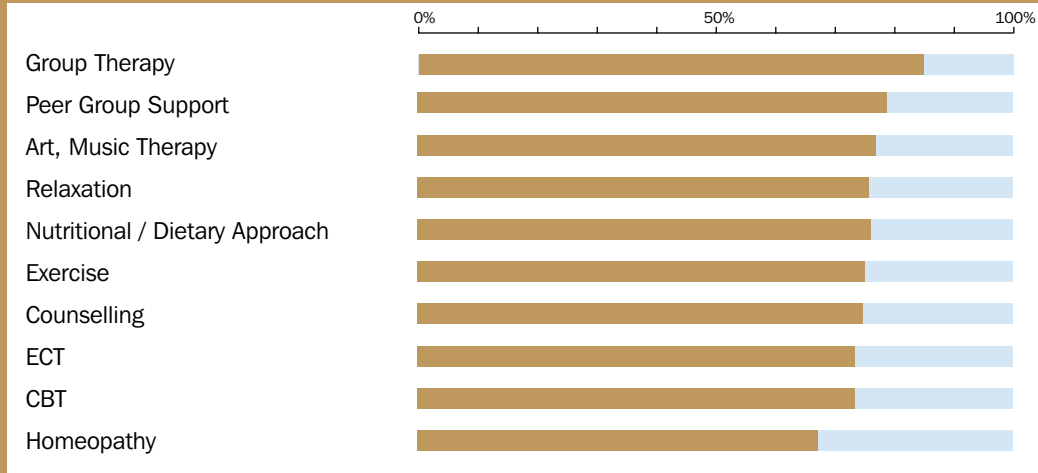
Table 11
Use of Alternative Treatments

Side Effect	Offered*	Tried when Offered**	Offered but Not Tried**
Relaxation	46.3% (192)	78.1% (150)	4.7% (9)
Art, music therapy	38.8% (161)	78.2% (126)	6.2% (10)
Group therapy	37.6% (156)	84.6% (132)	1.3% (2)
Counselling	35.2% (146)	76.7% (112)	4.1% (6)
Exercise	28.2% (117)	76.9% (90)	4.3% (5)
Peer group support	25.3% (105)	79.0% (83)	3.8% (4)
ECT	22.4% (93)	76.3% (71)	9.5% (6)
Nutritional/dietary approach	18.6% (77)	77.9% (60)	7.8% (6)
CBT	15.9% (66)	75.8% (50)	13.6% (9)
Homeopathy	5.5% (23)	65.2% (15)	21.7% (5)

* Calculated as a percentage of the total group

** Calculated as a percentage of the group who were offered the treatment.

Figure 7
Reports of Trying Alternative Treatments When Offered by Mental Health Professions



TRIED WHEN OFFERED ■

In addition, it was possible to identify those participants who had tried these treatments independently (i.e. without a formal offer from a mental health professional: see Table 12 below and Figure 8 on the next page).

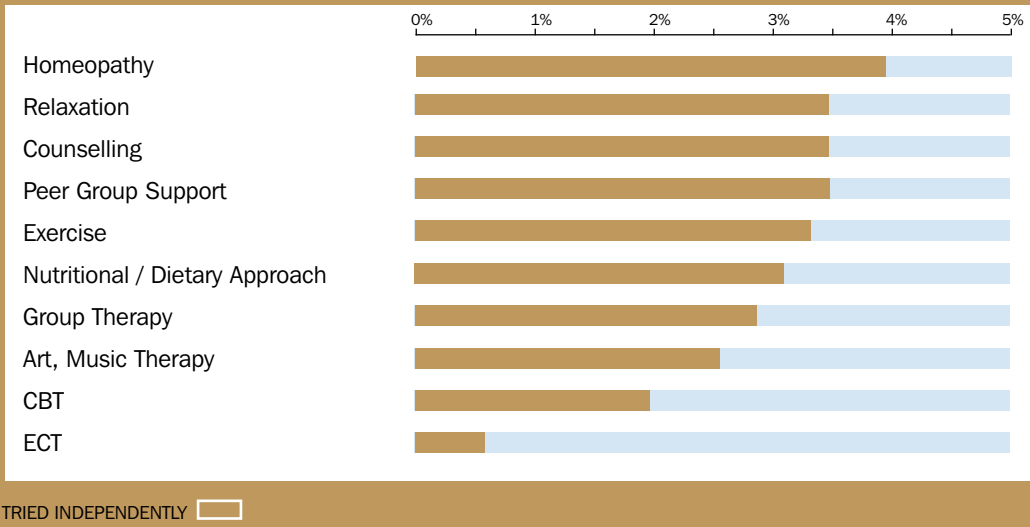
Table 12
Independent Use of Alternative Treatments

Treatment	Tried Independently*
Homeopathy	3.9% (16)
Counselling	3.4% (14)
Peer group support	3.4% (14)
Relaxation	3.4% (14)
Exercise	3.2% (13)
Nutritional/dietary approach	2.9% (12)
Group therapy	2.7% (11)
Art, music therapy	2.4% (10)
ECT	0.5% (2)

* Calculated as a percentage of the total group



Figure 8
Reports of Trying Alternative Treatments Independently



Having identified if they had tried one or any of these methods, participants were asked to report how helpful they found these approaches. Table 13 below reports the frequency of response for each as a percentage of those who tried the method.

Table 13
Ratings of Helpfulness of Other Approaches

Approach*	Very helpful/ helpful*	Neither	Unhelpful Very unhelpful
Exercise	88.2% (98)	6.3% (7)	5.4% (6)
Peer group support	83.8% (83)	6.1% (6)	10.1% (10)
Nutritional/dietary approach	79.5% (62)	11.5% (9)	9.0% (7)
Art, music therapy	77.5% (110)	14.8% (21)	7.7% (11)
Counselling	76.9% (100)	11.6% (15)	11.5% (5)
Relaxation	73.6% (126)	13.5% (23)	12.8% (22)
Group therapy	71.8% (107)	18.1% (27)	10.1% (15)
CBT	70.0% (42)	13.3% (8)	16.6% (10)
Homeopathy	66.7% (24)	11.1% (4)	22.3% (8)
ECT	49.2% (34)	20.0% (13)	30.8% (20)

* These figures are reported as a percentage of those who tried the method and answered the question on helpfulness and therefore may differ from the previous table.

Participants were asked who had recommended these other approaches. Just over half of the participants (51.3%, n=213) reported that the alternatives had been recommended by the consultant psychiatrist, 27.2% (n=113) had been advised by the CPN, 24.3% (n=101) were advised by their GP, 16.9% (n=70) by a friend, and 14.9% (n=62) by one of the Voluntary

Organisations mentioned earlier (see Table 8). However, looking across the categories 109 participants (26.3%) did not report anyone offering alternatives, 154 (37.1%) reported that only one person had offered alternatives, while the remaining 152 (36.6%) reported that two or more people had offered alternatives. In addition to this quantitative report, participants were asked to describe what alternatives each person offered to them. Looking at the responses, for each option (e.g. psychiatrist etc) a number of participants reported that this person had offered all of the options mentioned in the previous section, but some patterns were apparent. For consultant psychiatrists CBT/counselling, ECT and medication were frequent responses, while for the CPN art/relaxation therapy and counselling/group supports were noted. One notable pattern for GP recommendations was referral to psychiatric services. Recommendations from friends were broad but did include reference to exercise and diet. Finally, participants reported that voluntary organisations recommended other support organisations and peer group supports in addition to the other categories already mentioned.

Finally, an open-ended question asked participants to identify the factors that had affected their quality of life. Again responses were reviewed and key themes identified. There was a mix of both positive and negative comments here. Looking to the positive statements first, the most frequently cited theme was work or training (13.8%, n=57), closely followed by medication (13.3%, n=55). These themes can be seen in the following quotes, **“regular work after period of unemployment 10 years ago”** and **“the medication. It has stabilised the condition and enabled me to enjoy life much more than would otherwise be possible.”**

The next most frequent response was family and friends (7.5%, n=31, **“the love of my family, which has helped me to cope and bear the symptoms of my illness”**), followed by activities such as music, walking and exercise (4.1%, n=17, **“my hobbies are very important to me. I am very interested in the arts and find that they give me personal insights”**). Other factors reported included mental health professionals (3.9%, n=16, **“the help and support I received from mental health authorities”**), support groups (3.6%, n=15, **“my AWARE meetings-regularity of meetings. Support and freedom to express true feelings it has proved to be irreplaceable in my life”**), religion (2.2%, n=9) and therapy (1.9%, n=8). However 4.8% (n=20) described a factor as negative, and comments focused on side effects, such as loss of sex drive, lack of concentration and social factors such as isolation, as seen in the following quote, **“the most negative is my lack of family and the non-understanding of others.”**



METHOD

34 PARTICIPANTS

Overall, 415 participants completed and returned questionnaires. Within the group 63.6% (n=264) were male, while 35.9% (n=149) were female. Just over half (51.3%, n=213) lived in Dublin, with 46.7% (n=194) living outside Dublin. Reconsidering location, over two thirds were living in Leinster (69.9%, n=290) with 14% (n=58) in Munster, 11.1% (n=46) in Connaught, and 2.7% (n=11) in Ulster. The age of the group ranged from 12 years to 78 years, with a mean age of 42.61 (SD=11.99). Looking at the family and living status of the group Table 1 and Figures 1 & 2 report the key findings.

Figure 1: Marital Status

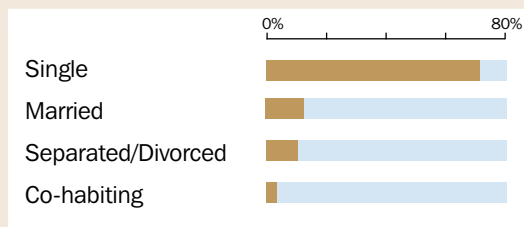


Figure 2: Participants' Reports of Having Children

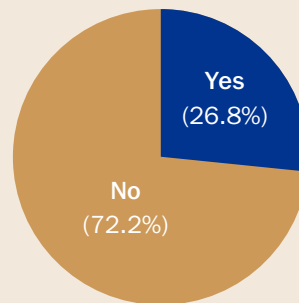


Table 1

Family and Living status

Demographic	Options	Percent	Frequency
Marital Status	Single	69.9%	290
	Married	12.5%	52
	Separated/Divorced/ Widowed	11.3%	47
	Co-habiting	2.7%	11
Do you have children?	Yes	23.6%	98
	No	64.6%	268
Living with	Family/Relations/ Friends	38.1%	158
	On your own	20.2%	84
Accommodation	Rented	25.3%	105
	Owned	27.7%	115
	Public	27.7%	115
	Private	10.8%	45
Living in Hostel	Yes	16.1%	67

Participants also reported the nature of their particular mental health difficulty. Where possible these were classified, however some participants (8%, n=33) did report multiple disorders. Overall, 46.5% (n=193) reported a diagnosis of a schizophrenia related illness. In addition, 33% (n=137) reported a diagnosis of an affective disorder.

Another 3.1% (n=13) reported an anxiety related condition, while 10 participants (2.2%) reported a developmental, stress related or eating disorder. Interestingly 4.3% (n=18) of participants reported they had not received a diagnosis or were unsure of the nature of their condition.

MATERIALS

A self-report mixed method questionnaire was designed specifically for use in the present study. The research team identified key issues in the research literature, which informed some of the key questions. In addition a focus group was conducted with the consultative committee, whereby a draft of the questionnaire was distributed in advance of the group discussion. The focus group identified a number of key questions and topics for inclusion.

The final version of the questionnaire contained seven main sections.

- Section 1 requested general demographic information, including age, gender, marital status, living arrangements, education and employment.
- Section 2 asked about frequency and quality of contact with family.
- Section 3 explored issues relating to quantity and quality of contact with mental health services.
- Section 4 asked questions about participants' relationship with mental health professionals, in addition to questions about their perception of communication with these professionals.
- Section 5 explored participants' knowledge of their diagnosis, their awareness of and contact with voluntary groups.
- Section 6 asked questions about the groups' experience of medication and side effects, including frequency and intensity.
- Section 7 explored participants' reports of other treatment options, as well as their general thoughts on quality of life and mental health services.

PROCEDURE

As with an earlier study funded by Schizophrenia Ireland (Farrelly, 2002), the questionnaire was distributed through a variety of networks. The major organisations of and for people who use mental health services were approached and invited to take questionnaires to circulate to their members.



The organisations approached were:

- AWARE
- Bodywhys
- GROW
- Irish Advocacy Network
- Mental Health Ireland
- Schizophrenia Ireland

Most agreed to take questionnaires to their regional groups, and in the case of Schizophrenia Ireland, this was supplemented by an article in their newsletter “SI News”. The exceptions were Bodywhys and GROW. Uncertain of how such a survey would be perceived by people who used their organisation, Bodywhys made the questionnaire available electronically on their website – thus visitors to the site could download and complete it and then submit to the research team. In the case of GROW, the organisation had recently completed a similar survey of their own, and felt there would be little or no interest in a further study at that time.

Providers were also approached from within both the medical service delivery system and rehabilitation settings. In most cases, there was a requirement for the study to be passed by the Ethics Committee of the organisation, even though it had already been granted approval by the Human Research sub-committee of the UCD Research Ethics Committee.

In some cases the delay this would have involved made it impractical to pursue possible questionnaire distribution with them. In the case of the service whose Ethics Committee did review the proposed study, access to service users was denied on the basis that those service users would not have the literary capacity to complete a questionnaire of such detail.

In the case of some rehabilitation settings where Ethical Committees were an issue, the providers were agreeable to exhibiting a poster produced by the research team which advertised the fact that the survey was taking place and invited service users to apply to the research team for a questionnaire to be sent out to them directly – thus avoiding any involvement for the providers themselves.

The questionnaire was also advertised on two nationwide social services electronic networks, and some members of those networks applied for questionnaires, which they would make available to those whom they served. A worker in a rural Partnership and a G.P, both of whom attended conferences where the research team was publicising the project, also took questionnaires to circulate.

THE RESEARCH TEAM

This study was funded by Schizophrenia Ireland and carried out by the Centre for Disability Studies in the UCD School of Psychology. The UCD research team were:

- Dr Michael Timms PhD, Principal Investigator
- Dr Suzanne Guerin PhD, Methodological Adviser
- Ms Lisa O'Farrell BA, Research Assistant

The Research Team itself was guided and supported by a Consultative Committee. This Committee comprised a member or members drawn from a number of support organisations, and they were:

- Mr John Bennett, AWARE
- Ms Liz Brosnan, Western Alliance for Mental Health
- Ms Kathleen Harding, AWARE
- Ms Colette Nolan, Irish Advocacy Network
- Ms Karen Penrice, Schizophrenia Ireland
- A Member, Schizophrenia Ireland
- Stephen Yeates, Mental Health Ireland

The Research Team wish to express their extreme gratitude to the members of the Consultative Committee for the knowledge and inspiration they have given toward the realisation of this report, and also to the funding body – Schizophrenia Ireland.



APPENDICES

38

PROMOTING CHOICE QUESTIONNAIRE

Thank you for taking the time to fill in this questionnaire. The questionnaire asks questions about your experience of medication and non-medication based treatments for mental health difficulties such as schizophrenia, bi-polar disorder (manic depression) and uni-polar disorder, amongst others. It also has questions which relate to your experiences of communication and relationships with health professionals. The results of this survey will be used to inform practitioners, doctors and policy-makers about what you think is good or bad in this important area. The overall aim of this research is to enable the development of a more informed and user-friendly service. Please answer all the questions in as much detail as you can. However, if you do not wish to take part in this study please return the blank questionnaire in the envelope provided.

The questionnaire is strictly confidential. You will see there is no space for your name and address. All information will be entered onto a database anonymously. However, if you are interested in participating in further research that we may be doing in the future, if you would like a copy of the results, or if you have any general queries, please contact Lisa O'Farrell on 01-7168416 or by e-mail at Lisa.Farrell@ucd.ie

PART 1: DEMOGRAPHICS

What is your age: _____ Gender: Male Female

Marital Status: Single Married
Separated, divorced, widowed Co-habiting

Do you have children? Yes No

Where do you currently live: (Please tick one box only for each section of the question)

With family/relations/friends OR On your own

In rented accommodation OR Accommodation owned by you/your family

In private housing OR Public housing

Are you living in a hostel or group accommodation provided by a mental health service/health board/voluntary housing association? Yes No

What county do you live in? _____

What is the name of the place (e.g. village/town) you live in? _____

Please indicate your highest level of education:

Primary school Third level certificate

Secondary school (Group Cert) Third level diploma

Secondary school (Junior Cert/Inter Cert) Third level graduate

Secondary school (Leaving Cert) Third level post-graduate

Post Leaving Cert Courses Other, please specify: _____

Have you ever taken part in an adult education programme? Yes No

Please indicate your employment status:

Fulltime paid employment Part-time paid employment

Voluntary work Full-time student

Unemployed Attending training centre

Government employment scheme Sheltered employment

PART 2: FAMILY

How often do you have contact with your family?

Always Often Sometimes Never

How supported do you feel by your family? (Place an X on the line below to indicate how supported you feel)

Very supported _____ Not supported

PART 3: MENTAL HEALTH SERVICES (QUALITY & QUANTITY)

Are you a public or private patient?

Do you feel there's consistency in the services you receive e.g. seeing the same psychiatrist every time? Yes No

Please explain your answer:

Please indicate how often you have seen these health professionals? (Please tick all relevant ones)

	Regularly since diagnosis	Once/twice since diagnosis	Never
Consultant Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatric registrar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Mental Health nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you ever received in-patient care		Yes <input type="checkbox"/>	No <input type="checkbox"/>

If yes, how would you describe the quality of the treatment you received? (Place an X on the line below to indicate your answer)

Very good _____ Very poor

Have you experience of aftercare following discharge? Yes No

Please explain what type of aftercare:

How would you describe the quality of the aftercare you received? (Place an X on the line below to indicate your answer)

Very good _____ Very poor



Have you ever needed to access services outside of office hours/in an emergency situation? Yes No

Do you feel you have rights in terms of your mental health? Yes No
Please explain your answer:

Are you aware of the legislation on mental health? (eg. Mental Treatment Act 1945, Mental Health Act 2001) Yes No

Have you experience of involuntary detention? Yes No

If yes, were you aware of the legislation on mental health and your rights at the time? Yes No

PART 4: COMMUNICATION & RELATIONSHIP WITH HEALTH PROFESSIONALS

Who do you see most often for your mental health difficulties? (*Please tick one only*)

GP Consultant psychiatrist
Psychiatric registrar Community mental health nurse

Who do you talk with most often about your mental health difficulties and your treatment (*Please tick one only*)

GP Consultant psychiatrist
Psychiatric registrar Community mental health nurse

The following questions relate to the person you talk with most often about your mental health difficulties and your treatment and they refer to him/her as "this person".

How often does this person talk to you about your medication?

Always Often Sometimes Never

Please indicate how often this person discusses each of the following issues with you:

Always Often Sometimes Never

Effectiveness of the medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Why you are on that particular medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Possible side-effects of the medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alternative medications to the one prescribed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Role of medication in your treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How long you will be on medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Has this person given you a written record of your medication and when to take it? Yes No

Has this person given you written information about possible side-effects? Yes No

Do you feel that this person possesses adequate education in mental health? Yes No

How would you describe the quality of your relationship with this person?

- Very Good Good Neither good or poor Poor Very poor

Please explain your answer:

How often does this person offer you a choice of medication?

- Always Often Sometimes Never

How often does this person offer you a choice in your treatment?

- Always Often Sometimes Never

If you were offered choices, what choices were you offered?

If not, what choices would you like to have available to you?

How involved do you feel in your treatment?

- Very involved Involved Not very involved Not involved at all

What would be your hopes for your future treatment/recovery plan?

Overall, how would you rate the quality of your treatment with this person?

- Very Good Good Neither good or poor Poor Very poor



In general, how important do you think the following characteristics are in a good mental health professional?
 (For each characteristic below place an X on the line to indicate how important you feel it is)

Trust	Very much _____	Not at all
Equality	Very much _____	Not at all
Competency	Very much _____	Not at all
Someone who will listen	Very much _____	Not at all
Someone who will explain	Very much _____	Not at all

PART 5: KNOWLEDGE

At what age did you have your first episode? _____

How long after this did you first see a health professional (e.g. GP, psychiatrist) for your difficulties?

How long since your first contact with a health professional before you received a diagnosis?

What is your diagnosis: _____

Please describe your understanding of recovery from mental health difficulties?

How often has your doctor (e.g. your GP or psychiatrist) discussed the idea of recovery with you?

Always	Often	Sometimes	Never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you know the name of your consultant? Yes No

For each of the groups/organisations below please tick the box if you have heard of them, or if you have had contact with them:

	Heard of	Contact with	Heard of	Contact with
Schizophrenia Ireland	<input type="checkbox"/>	<input type="checkbox"/>	Aware <input type="checkbox"/>	<input type="checkbox"/>
Mental Health Ireland	<input type="checkbox"/>	<input type="checkbox"/>	Samaritans <input type="checkbox"/>	<input type="checkbox"/>
Irish Advocacy Network	<input type="checkbox"/>	<input type="checkbox"/>	Grow <input type="checkbox"/>	<input type="checkbox"/>
Other _____				

In general, how would you describe the quality of your contact with these services?

Very Good	Good	Neither good or poor	Poor	Very poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please explain your rating:

PART 6: MEDICATION & SIDE EFFECTS

Are you currently taking any medicine for mental health difficulties? Yes No
 If yes, what medicines are you currently taking?

Have you ever stopped taking your medication or reduced the dose without the support of your doctor (e.g. GP/psychiatrist)?

Stopped Yes No Reduced Yes No

If yes, what was the main reason for this?

How did this decision work out for you?

Has your doctor (e.g. GP/psychiatrist) ever offered to help you come off your medication?

Yes No

How often has your doctor (e.g. GP/psychiatrist) asked you if you were experiencing any side effects from your medication?

Always Often Sometimes Never

Please fill in the table below. These questions ask about 'current' medicine for mental health problems. Please take the word 'current' to mean 'anytime in the last twelve months'.

Side Effects	Have you had this	How bad was it for you?			Which medicine were you taking at the time
		Tolerable	Bad	Very Bad	
Example	Yes		✓		Name of Medication
Muscle spasms					
Shaking/tremors					
Feeling of inner restlessness					
Weight Gain					
Loss of Energy/ tiredness					
Sexual side-effects					
Effect on eyes					
Dry mouth/thirst					
Poor concentration					
Other					



If you haven't experienced any of these side effects in the past 12 months, can you think of a period where you experienced similar side effects to the ones described? Yes No

If yes, what were the side effects? _____

How do you account for the fact that you are no longer experiencing these side effects?

Overall how would you say side effects affect your everyday life?

Not at all

Not much

A lot

PART 7: OTHER TREATMENT OPTIONS

This section is about treatments other than medication, which are used in mental health. Please fill in the table below

Other Treatments	Have you been offered this?	Have you tried this?	How Helpful Was This For You?				
			Very Helpful	Helpful	Neither Helpful or Unhelpful	Unhelpful	Very Unhelpful
Example	Yes	Yes		✓			
Cognitive Behavioural Therapy							
Counselling/ Psychotherapy							
Group Therapy							
ECT							
Peer Support Group							
Nutritional or Dietary Approaches							
Art, Music or Other Creative Therapy							
Homeopathy or Herbal Medicine							
Exercise or Other Physical Therapy							
Relaxation Therapy or Meditation							
Other							

In relation to the above treatments, please indicate who advised you of/referred you to these services?

- Consultant Psychiatrist/Psychiatric Registrar What Treatment: _____
- Community Mental Health Nurse What Treatment: _____
- GP What Treatment: _____
- Friend What Treatment: _____
- Group/Organisation (see pg. 5) What Treatment: _____
- Other What Treatment: _____

If you had to name one thing, which has made the most difference to your quality of life, what would it be?

In your opinion, what changes to current mental health services would have the greatest benefit for peoples mental health and well-being?

Any other comments:

When completed, please use the FREEPOST envelope provided or post to:
Lisa O' Farrell, Centre for Disability Studies, University College Dublin, Belfield, Dublin 4.
A copy of the above report will be available from the above address during the Summer of 2005.

THANK YOU



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