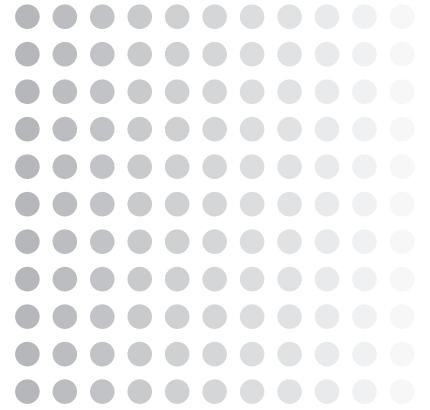


WHAT PART OF THE PICTURE?

Perspectives of Service Users and Carers on Partnerships within Mental Health Service

Report by
The Research and Resource Officer
of the Western Alliance for Mental Health
Liz Brosnan





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Foreward

The Western Alliance for Mental Health is committed to the promotion of positive mental health in the West in a spirit of partnership and co-operation. The Alliance believes that solutions for people with mental health needs lie in establishing effective partnerships.

Supported by Health Services Executive Western Area, the Alliance were given the unique opportunity to embark on this piece of research which has sought to establish the nature and extent of partnerships as perceived by those who directly experience mental health services, namely users and carers.

The report presented here provides a voice from service users, often unheard in the planning of mental health services. Its conclusions are considered relevant for the development of future services and it is vital that the challenges presented are grasped in any future strategies for the provision of mental health care in the West.

The research has highlighted that partnerships take different forms in mental health care. There is considerable scope for future development of both strategic and therapeutic ways of working. An over-riding issue is the need for better communication and consultation. This would be a large step towards developing a recovery approach within the region.

The study was initiated in 2003 and this is the final component on research and partnerships undertaken by the Alliance. While the Alliance itself is a partnership of ten or so like-minded, non-statutory, care organisations, the group is indebted to the diligence and expertise of its resource officer, Liz Brosnan, who undertook the research. We would also like to acknowledge the vision and support of the HSE Western Area for enabling the project.

Recommendations are without meaning unless they are fully embraced. The challenge we present is to all those involved in using and providing mental health services, we must work together to develop and implement an action plan.

Yours faithfully,



Gerard O'Connor

Chair,

Western Alliance for Mental Health

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Executive Summary

Partnership with people who use mental health services is a key component of best practice for delivering meaningful services that are appropriate and relevant for those who use them. This report, the final component of the Partnership Research project, carried out by the Research and Resource Officer of the Western Alliance for Mental Health, seeks to answer the question: what does partnership mean to users of mental health services in the HSE Western Area? Five focus groups were carried out with people who use these services and some people who care for them (forty people in total), to explore their experiences of partnership with the services they use.

Key findings from the focus groups with people using the mental health services can be summarized as follows:

- **Partnership:** there was little evidence of either therapeutic or strategic partnership.
- **Communication:** in general, communication with service users was experienced as poor.
- **Obstacles to Communication:** included staff being too busy or perceived as uninterested.
- **Consultation:** people mentioned advocacy meetings in an acute unit, or being consulted about activities in training centres, but in general a lack of consultation was reported.
- **Experts by Experience:** no one reported that their own experiences of staying well had been inquired about by staff.
- **Care Planning:** for some it was conducted inappropriately, while others felt excluded.
- **Key Workers:** the lack of a key worker was highlighted, with participants outlining some obstacles to developing this important relationship.
- **Staff Attitudes and Behaviour:** there were different comments made about the impact staff's attitudes have on a service user's life, both positive and negative.
- **Medication:** key issues were the lack of consultation about medication, little or no information on side effects, feeling compelled to take medication, feeling that medication doesn't work.
- **Support outside Office Hours:** participants reported that they had received no practical help or support in dealing with fellow service users going through a crisis.
- **Fear of Relapse:** this was one of the most specific fears that people spoke about, the constant worry they had of a relapse, of becoming ill again and how this impacted on their lives.

- **Work and/or Training Centres:** people talked about the importance for them of work, and training centres. They found it to be helpful for recovery, becoming well and staying well, and they also found lack of access to work frustrating and stigmatising.

- **Experiences of Discrimination and Stigma:** people recounted being discriminated against when seeking employment because they were mental health service users. Stigma had a major impact on people's ability to find work or be open about their health status in work.

- **Relationships:** people spoke about the impact of their mental health difficulties on relationships, and their experiences of illness affecting their ability to create and sustain relationships.

- **Relationships and Stigma:** many comments refer to the impact of stigma on friendships and other significant relationships. Stigma resulted in these people feeling judged, lonely and ashamed, and contributed to a feeling of bringing shame on their families as well.

- **Anti Stigma Measures:** some suggestions were offered to combat stigma and to demonstrate that if people in the wider community have contact with services and the people who use them, this changes their perceptions of mental health service users.

Key findings from the carers' focus group with can be summarised as follows:

- **Lack of Involvement:** carers did not feel involved in decisions about the care of their family member.
- **Lack of Support:** carers did not feel supported by the mental health services.
- **Lack of Structure:** carers had no sense that there was a structured approach to dealing with their family member.
- **Doctors:** carers had mixed experiences with doctors.
- **Sector Boundaries:** carers were frustrated by the division of services into sectors, with the resultant lack of choice.
- **Stigma:** affected many carers ability to be strong advocates for the needs for their relative.

- **Involuntary Admissions:**

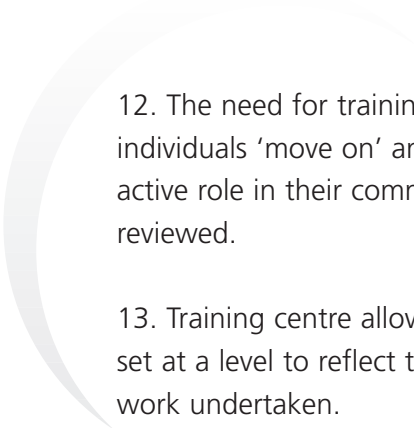
the issue of having to sign a family member into hospital against their will was a difficult and upsetting experience

- **Voluntary Sector:** carers reported receiving information and support from the voluntary sector.

Recommendations:

It is hoped that these recommendations will be used to develop an action plan for the HSE Western Area, utilizing a partnership approach, to ensure that these changes are achieved in a timely and effective manner.

1. Strategic partnerships should be developed at local, regional and national levels of the mental health services. These partnerships should be developed using the National Disability Authority strategic partnership guide.
2. Mental health service provision should include the concept of therapeutic partnership as a core component and be an explicit element of the care planning process.
3. Dignity, respect and equality should be the cornerstone of delivery of mental health services. These values should be incorporated into a vision statement for the services within the reformed HSE structures and built into the service planning process.
4. Training on the principles of recovery should be developed and delivered to all mental health services in the region.
5. The care planning recommendations in *A Vision for Change* need to be addressed. An action plan needs to be developed for the HSE Western Area using a partnership approach to ensure that this is achieved in a timely and effective manner.
6. Systems to facilitate communication between staff, service users and all those involved with their care to be developed.
7. All mental health service users should be allocated a key worker and the therapeutic benefits of this relationship should be regularly reviewed.
8. Respite facilities should be a specific component of the HSE's move towards community based mental health services.
9. Actions to tackle stigma need to be developed and prioritized. Service user involvement must be a key component of these initiatives.
10. The role of voluntary mental health organisations and support groups should be recognized and actively promoted by mental health service staff to ensure that service users and carers can access this support.
11. The feasibility of developing alternative approaches to placing mental health service users in employment should be investigated.



12. The need for training centres to help individuals 'move on' and take up a more active role in their community should be reviewed.

13. Training centre allowances should be set at a level to reflect the value of the work undertaken.

14. Efforts should be made to ensure that complaint procedures and systems for customer feedback should be user-friendly and easy to access by both service users and carers.

Introduction

This report is the final component of the Partnership Research project, carried out by the Research & Resource Officer of the Western Alliance for Mental Health. It seeks to answer the question: what does partnership mean to users of the mental health services? The two previous reports on partnerships (*Partnerships in Mental Health, Report Part 1, and Part 2, Brosnan 2003, 2005*) looked at what service providers understood by partnership. These reports examined the current situation regarding partnership as a way of working throughout the mental health services.

This final phase of the project sought to determine service users' and carers' experiences in relation to partnerships, to explore how they perceived their relationships with staff and the services. *A Vision for Change: Report of the Expert Group on Mental Health Policy* (Department of Health & Children, DOHC, 2006) addresses the principle of involvement of service users and carers in mental health services. 'Service users must be at the centre of decision making at an individual level in terms of the services available to them, through to the strategic development of local services and national policy.'

Two major categories of partnership were identified at the outset from the earlier work. These were the therapeutic alliances or personal relationships people have with the staff, and strategic partnerships, i.e. the inclusion of users and carers in forming a long-term plan to achieve a specific purpose. We looked for evidence of partnerships between the service providers and service users or

carers; how people experienced their individual relationships and to what extent they felt involved in planning or evaluation of services.

The Steering Group for this Partnership Research Project consists of Ms Helen Dempsey, Development Officer for Mental Health Ireland, and Line Manager for the post; two other members of the Western Alliance for Mental Health: Ms Margaret O'Connor, Deputy CEO, Irish Advocacy Network and Mr Mark Logan, Regional Manager, Rehabcare; Dr David Evans, Senior Research Officer, Dept. of Population Health, Health Service Executive (HSE) Western Area. Ms Aideen Lovett, Field Worker, GROW, joined at a critical stage towards the end to help with getting the report into the public domain.

Acknowledgments

The contribution and dedication of the steering group to the research process of this Partnership project has been invaluable, and completion of the final report would not have been possible without their constant positivity and enthusiasm for seeing this project to completion. Many thanks also to all who participated in the focus groups, and those who facilitated them by informing people, and even arranged transport for those willing to attend.

The vision for meaningful partnerships within mental health services for all who work in or alongside the services, and those who use them or are affected by them, has been the guiding light and motivating force behind this questioning of how services are currently delivered and experienced.

Methodology

2.1 Introduction

During the first phase of consultation with the staff and service providers about their experiences of partnerships, several different understandings of partnership were evident. We refined the definition of partnerships between users and carers to look at two broad distinctions: how people are involved in their own care and, on a broader more strategic level, how people might be involved in service planning, i.e. 'moving beyond consultation'. These were used as the basis for generating discussion in the focus groups to elicit the experiences of service users and carers.

Strategic partnerships are about improving the service for everyone, and involve forming a long term plan to achieve a specific purpose. They may include working through committees or working groups to examine policy or service developments and should be inclusive of all stakeholders, including service users and carers. A comprehensive guide to working in partnership with people with experience of mental health difficulties was produced in 2005 for the National Disability Authority (NDA). This guide reviewed best practice and produced guidelines to address many of the difficulties inherent in working in true partnership.

Therapeutic partnerships are by definition more personal, so we examined the individual's relationship with the service

providers, and the support received for the individual's recovery process.

Focus groups of services users and carers were convened to obtain information about their experiences in relation to partnerships. Four groups were carried out with service users, one in each mental health service area. Carers are a major stakeholder with their own unique insight into services and play an important role in supporting service users. Therefore it was decided to involve their perspective through a separate focus group.

2.2 Recruitment of Service Users to Focus Groups

Since there is no available database of mental health service users within the HSE Western Area which could have been used to identify participants, different methods of recruiting participants were discussed during meetings of the steering group. Displaying posters and placing advertisements in the local papers inviting self-selection of participants were considered but ultimately decided against, as this approach had not been found useful in motivating people to come forward for previous studies. In order to ensure sufficient participants with diverse experiences, various staff were identified who were in contact with people who had used the services, and their co-operation in nominating participants was sought. It was felt that people volunteering to participate through this contact would be motivated enough to make the effort required to attend focus groups.

The staff identified were based in the community, working either as community mental health nurses, or in supported housing, training centres or drop-in centres. People working with the voluntary and self-help groups were also contacted to enlist their assistance in recruiting participants. People currently using acute services were not included for ethical reasons, but participants had earlier experience of attending acute units.

Thirty-one letters in all were sent to these contacts, requesting that they discuss the project with people they worked with and ask for volunteers to take part. Staff were asked to return to the researcher the names of people who indicated willingness to take part. A follow-up phone call ensured that they understood the nature of the request. In particular the need was emphasized to obtain a representative cross sample of participants, not just people who were either very positive or negative in their opinions. A consent form and a covering letter with information on the project were sent to the staff to give to potential participants. Once these were signed and returned with contact details, individuals were then contacted to determine their interest and availability. A total of 43 signed consent forms were returned by service users.

Senior management were informed about the project and the proposed method of recruiting participants.

2.3 Recruitment of Carers to Focus Groups

Recruitment of carers was somewhat less formal as a signed consent form was not sent to the researcher. Instead, the staff involved in working with these people in support groups made contact with potential participants and the carers then contacted the researcher themselves by phone, indicating their interest and availability.

This process resulted in a group of seven parents of young adults with a similar diagnosis of schizophrenia, as these were the carers most closely engaged with the support groups offered by Schizophrenia Ireland.

2.4 Planning the Focus Groups

In order to ensure consistency between the groups a detailed topic guide for the discussion was developed, with prompts to help elicit information or to clarify the meaning of a question.

The concept of partnership was simplified, in the information presented to the groups, into two key components: their therapeutic relationships and more strategic partnership relationships. Their experiences of being partners in their own care were the first aspect of partnership discussed. We explored whether they had experienced being asked what helped them stay well, whether they felt they were treated as equals in their care. Feedback was offered on what staff had said was

important in making partnerships work well: good communication, mutual trust and respect, and feeling equal. A number of prompting questions around these issues were developed in order to stimulate feedback and discussion from the participants.

We also sought to obtain information on participants' experiences of being involved in strategic partnerships, whether people had had any experiences of being involved in planning how services are delivered or shaped. Again prompts were developed to expand this concept for people and to offer concrete examples.

It was decided not to pilot the topic guide used to refine the questions posed to the groups due to time constraints. There was also an issue about the available pool to draw from for a pilot group, due to a limited number of names submitted by staff in the area, and it was considered that service users should not participate in both a pilot and study group. Instead the questions and notes for the format were reviewed by the steering committee and individual service users.

All participants were assured of complete confidentiality in whatever was said during the groups, and that any identifying information would be removed in what was written up about the discussions afterwards. A commitment was made to circulate the report on the findings of the focus groups to all participants who wished to receive it and who put their contact

details on a form for this purpose. Many participants, both service users and carers, expressed a need for further meetings and opportunities to discuss their concerns.

The five discussions were recorded and complete transcripts prepared of the focus groups, which were then analysed. A decision was made to remove identifying information about individual members of staff and individual services which could lead to participants being identified. Common themes and concerns expressed were identified and are presented below.

2.5 Participant Profile

Four groups of service users were finally convened and their opinions about partnership, or their relationships with the mental health services, were explored through open semi-structured discussions. One was held in each mental health service area; Galway city; Loughrea, Co Galway; Castlebar, Co Mayo, and Roscommon town. A neutral venue was used in order to encourage the groups to discuss freely. A total of 33 service users participated in the four groups.

While no specific demographic information was collected from participants, the ages ranged from people in their early twenties to someone over sixty five, 63% of participants were male, and everyone had been using the mental health services for at least two years.

Focus Groups with Service Users

3.1 Introduction

Four focus groups with service users were held throughout the HSE Western Area to explore their experiences of partnership with the mental health services. A number of themes emerged from this process, which will be presented and discussed in turn.

3.2 Experience of Partnership

Analysis of the content of the focus groups offered no clear evidence of service users being, or even expecting to be, treated as partners in their care. There were many anecdotes of good practice in communication, being listened to, being consulted about their opinions or wishes in individual situations by particular members of staff, but on the whole the four groups offered little evidence that a partnership ethos was present in their contacts with the services. Many participants suggested that an unequal relationship exists between service users and staff.

What the staff, the majority of the staff, do is take away three things that you need in this life, number one is dignity, number two is self-confidence and number three is self-esteem, you cannot live a life without them, so you're not equal.

It was evident that the term partnership was not clear to the participants, or relevant to their experience. The concept of equal, respectful relationships was substituted in order to engage and stimulate the group discussions. This concept was more identifiable but, on the whole, outside their general experience of care within the services.

3.3 Communication

The issue of communication came up in each of the groups. The service users had many opinions about their experiences of communicating with staff. There were positive comments on individual aspects of the services, some staff groups, the ethos in a particular centre, or programme, e.g. a Clozaril clinic. People spoke about the support they received from regular group discussions, and others from individual staff members.

So that's given my trust back because if I say that I don't want them to ring my mother they won't, you know, I think there is nothing worse than if someone is fragile to take that little bit of trust away. I find (a named centre) they're just so good they always ask me first and say, you know, we are going to try this medication, are you happy with it, they ask my opinion, they don't just, you know, sometimes they say we have got to take it out of your hands you are not capable, but they will tell you they are taking it out of your hands as well, there's none of this behind your back, you know, which makes me feel comfortable.

In general however, with some exceptions, the comments are about not being listened to or acknowledged.

I've given up trying to talk to nurses except for one, I found it very unhelpful, upsetting. I've gone to them suicidal and I've been blanked more than three or four times and I've just given up trying to talk to them at all. The same goes for a lot of the others.

If they listened and actually talked to you in return you know, and blanking you, judging you, that's not nice. But if they actually listened and responded and talked to you, had a conversation with you, a two-way conversation, that would be nice.

Like doctors and nurses can only do so much but they've got to be able to listen to us as well and I find that's a very big factor and it's a lean factor in a lot of places. I myself have tried to sit down and talk to them about my (Named condition), they don't want to listen and I feel very hurt when I find that what I say to them is still not being taken into consideration, that it has been a waste of time sitting down to discuss something that they're not listening to.

3.4 Obstacles to Communication

Some of the obstacles to communication mentioned are: staff being too busy or disengaged from their work, just 'punching in time'. Other comments suggest lack of awareness by nurses, or work practices which do not appear to be

conducive to good communication. Some people highlighted the fact that nurses stayed in their work stations and did not come out to interact with service users.

Now I'm not saying that the staff were bad, I'm saying that the system, the way it was, it wasn't set up for comfort.

But is that because they haven't time, or what is it? If they haven't time for a good chat, you'd wonder like, I know there's a lot of us feel mental illness a little bit but you'd appreciate that, have a chat one-to-one, treat me as an equal, as a person besides your disability but I suppose they're so busy, there's so many people to see, I mean, is that why?

There's a few individuals, well there isn't too many now, one or two individuals in (specific centre) and they don't want to talk to you at all, they don't want to know, they just want to be there and do their job and go, get out as quickly as possible you know, once they punch in hours, they don't want, they're not interested in patients.

I do find in the unit that the nurses seem to be in a bubble in the office observing us and things like that but they never actually came into the smoking room and had a fag with us, sat outside and had a chat, you know they never really integrated.

This was particularly noticeable when service users spoke about their relationships with doctors. They highlighted obstacles such as lack of

continuity of care, the frustration of having to frequently re-tell their history to new doctors, of inadequate levels of communication with doctors, where doctors talked over their head to carers, or where they felt the doctor was not interested in their quality of life, rather presence or absence of symptoms.

There was a lot going on, I'd seen four or five different psychiatrists. Then you go in to talk to them and you've got to tell your whole story over again. I feel like saying read my file you know, because I'm agitated anyway, so I find that hard sometimes, when the pattern is broken, you know, if you've got to see different people and they are asking you all the old stuff that is hard to talk about, it's every week someone different.

They don't really care about your standard of life, as long as you're taking your medication, sleeping and eating, that's all they care about. They don't care about your standard of life, how you're living and where you're living and what kind of life you have, they don't even talk to you about it, you know.

3.5 Consultation

Participants were prompted to talk about being consulted on their ideas and opinions, or their experience of staying well, and what might have helped them stay well. People mentioned advocacy meetings in an acute unit, or being consulted about activities in training centres, but in general a lack of consultation was reported. Some people reported having their goals set for them

by staff, whereas others were asked what goals they wished to set.

Just with the advocacy in the hospital, had an advocacy meeting, just at that, that was the only time.

...they do that, if you're on training, if you're on sheltered work they don't do anything like that, but if you're on training, they do that every three months and you can kind of set your own goals if you want.

Some of the instructors set their own goals for you and some of the instructors ask you what you want your goals to be.

One person stated:

I think that service users, us, should have an important part in drafting any sort of policy, legislation or course designed to help us.

3.6 Experts by Experience

In each group the question was raised about whether they had been asked what helped them stay well, about their experiences in managing their own mental health. It appeared from the comments offered that they had not been consulted. Each group responded to that prompt by offering ideas about what they thought might help them in recovery such as exercise, losing weight, work or being occupied. There was no evidence of consultation about what worked for them. None of them reported that their own experiences of staying well had been inquired about by

staff. In some instances users knew what might help with their recovery, but were not facilitated by staff who were too busy.

There's very very little emphasis put on fresh air and exercise, you know, very rarely, I'd say well can I go out for a walk, well not without a nurse, and then you have to wait the nurses are busy and they might never get a chance to go out with you, and you know, you're stuck in for the day, where exercise should be one of the key points in our recovery, you know, it's not, because they said oh you need a nurse to go with you but sure they're never there to go with you.

3.7 Care Plans

Some people commented on care plans and in general it appears there is no standard approach, that care planning appears haphazard if present at all. Some people feel excluded from the process of care planning, whereas for others it was conducted inappropriately. One individual highlighted the fact that she had a care plan but the lack of privacy in developing it created a lot of anxiety for her.

I was supposed to be going to do a care plan but it hasn't happened yet, there's talk about it from the nurse. I think they think because I'm in college I don't need to; you know, if I'm coping with college I must be doing okay, and I am, but I still need someone to talk to. You need someone to help you with your care plan and that, so I feel kind of left behind in that, I'm put on the long finger you

know, it hasn't been made a priority for me. ...But she just said I have to do a care plan but that's months ago and it hasn't happened since. I'm coping like, I'm coping without it but you feel sometimes you're being a little bit forgotten.

I found that a different care plan was done every time, so there was no actual reference, integration into one care plan, the three times I was in hospital it was three different care plans. You couldn't build up a bond because there was no actual one-to-one with your nurse either, it was done with the other patients around, so you were on a four bedded ward or a six bedded ward and the nurse would sit down with you and all the others are around listening in and, and, it's like you didn't feel, that feeling of safety, you know, that you could open up.

3.8 Key Workers

The lack of a key worker was highlighted, with participants outlining the obstacles to developing this important relationship.

You don't actually build up a relationship with the nurses in hospital because you get a different nurse each time, well look how can you build up a relationship if you get a different nurse every time. Whereas if you build a relationship with one nurse then you actually become, you know, more, a deeper level of intimacy, so you actually get to the roots of problems and things like that.

3.9 Perceptions of Equality

There was an interesting observation made about how uniforms and titles can place barriers between staff and service users. One person with experience of using services in another country made the following comment.

...so it would be brilliant if it could be equal, not in rank, but in like (other country) really, like I've been out on the exchange programme to (other country), there the nurses are dressed in jeans and a blouse, that's equal, you know. Now I'm talking about you know, the unit we'll say would say be the equivalent, eh here they're dressed in a uniform and automatically there's an attitude going with it from my history, and that automatically stops communicating and trusting, but if they're dressed like we are we're equal, also the doctors they're called by their first name...

Another participant said that people were afraid to speak out:

We're users of the services and they're way above us you know, if we were equal, the communication lines would be open, which they are shut. A lot of users of the services won't actually say that because they're afraid but they do state it amongst themselves, so, that's one way it could be equal like, you know if the communication lines were open, you'd feel just together like...

3.10 Staff Attitudes and Behaviour

There were different comments made about the impact staff's attitudes have on a service user's life. Some positive things included being listened to and treated respectfully and how this makes them feel, see earlier comments in 3.2.

However negative comments included not being listened to or treated in a way that made the service user feel diminished. Two particular comments highlighted abusive behaviour.

*He started roaring and shouting at me. He was disturbing me. He started roaring and shouting at the top of his voice. You could hear him a mile away down the road. (Another participant mentioned by name) heard him and everybody else here heard him 'Get out, get out' he said, 'what are you doing', I was lying in the bed you see, and I was watching TV. But he rushed in and he started roaring 'Get out Get out' really loud like and this and that. I walked out and then he came outside after me 'what are you doing, you go now, you are not wanted here' and all this. I think you should know that I am not making it up and if you think I'm making it up ask any of them out in the (named centre) and they will tell you the truth he came in shouting and roaring I reported him before to Dr ****. Now he is started again you know. He really disturbed me when somebody roars it really gets me going. I would not make it up, I would not say it unless it was true. That is what I have to say.*

Another person added:

I had two particular people, I won't mention names now but both of them now was fairly aggressive they would come with a pillow and you could probably guess what they would do with the pillow. One particular fellow was very devious altogether, a full rattle of the pillow you would get out of it. It was not a nice thing to come around eight o'clock and belt you out of the bed.

3.11 Other Concerns Discussed

Although the focus of the research was to explore what people had experienced of partnership, and their experiences of relationships with staff and the services, the service users had many other issues of equal concern to them. Frequently other topics generated as much discussion: issues such as medication, stigma, the importance of work, and relationships in general, not just with staff, but with each other and family members. Another issue of major concern was access to support outside office hours. Several people spoke of difficulties obtaining help for people they had reason to be very concerned about during night hours.

3.11.1 Medication

People had a lot to say about their medication, about their attitudes towards it and the side effects. The comments given in this section offer some insight into how service users perceive their relationships with staff and the services,

and indeed the medications they are prescribed. Key issues that emerged were the lack of consultation about medication, little or no information on side effects, feeling compelled to take medication, feeling that medication doesn't work.

I think the day you rely on the tablets to do the hard work and effort for you to change yourself and your life is the day you get a sad hard blow, because it doesn't work.

...you're put on medication and you still have the same problems, you know, with you being on medication. They don't go away, so how do you know that the medication is doing any good at all?

...medication you know, doctor just puts you on medication and you more or less have to take it or we'll get punished for it. We'll put you into (specific old mental hospital named).

...listen, not one doctor has said to me about medication, what is the side effects, never told me what's the side effects, you know, they expect you ask everything, you know, they won't tell you.

3.11.2 Support outside Office Hours

Participants reported that they had received no practical help or support in dealing with fellow service users going through a crisis. One woman related how she had to take someone to an Accident and Emergency department 30

miles away during the night, although they were living in a house provided by the local mental health service.

I've had three cases of (attempted) suicide in the last couple of weeks and I had to deal with it myself for them and I was told to take them to hospital. There's no back up service...if someone gets sick at night.

Another person added:

... a friend, who I had been in hospital with, was very sick and I rang the unit and said, look he's very sick. I rang the day centre first during the day and they didn't contact him or anything, they tried to contact him on his phone but that was all they did. Then I rang the unit that night and said, look, he's suicidal at the other end of the phone. He was in (named town 15 miles from the adult mental health unit) and they said that they couldn't do anything. So they said, get him to hospital, which he was refusing to do. I had no transport so I had to borrow a car and go over. I had to bring a friend with me to forcibly try and get him to the hospital. I persuaded him to come to the hospital in the end but it took an hour and a half. I actually rang the unit while I was with him and got him to talk to them and that. But the response was that, that's all they could do, which was talk to him on the end of the phone. They didn't even ring like you know, there was no like emergency cover like a community nurse or something to cover situations like that and then I had to bring him to the hospital and wait with him.

Having somewhere to go is identified as an unmet need. Comments suggested that having somewhere to go could allow time for a difficult or tense situation to diffuse. It could also prevent the need for admission to acute care.

My mother often said 'we often have rows, and I think you should have a place where you could go to when you are not fully sick to go into hospital but not well enough to be at home'. There should be accommodation for people like that. A hostel or something like that.

3.11.3 Fear of Relapse

This was one of the most specific fears that people spoke about, the constant worry they had of a relapse, of becoming ill again and how this impacted on their lives.

I can't still enjoy what I've got now because I am always afraid in the morning when I wake up, is it going to be as bad, am I going to lose my daughter, I've lost three children due to depression and it's always in the back of your mind

...the biggest fear of all psychiatric patients is to get sick again and end up in hospital. And a lot of them won't go off medication in case they get sick again.

I hope I don't go down you know. I don't wait for it, do you know what I mean, I get on with my life but it really struck me that I could get a dose of that again, you know.

3.11.4

Reasons for Initial Contact

Accounts of some of the reasons why people became involved in the mental health services in the first place are disturbing and raise many questions about pathologizing mental distress or trauma.

I had a bad experience a couple years back. I worked in the post office and I was involved in an abduction, you know, and since that whatever it done to me it messed me up completely, you know, it messed me up bad enough to be in a psychiatric hospital for a year. At that time they were giving that electric shock treatment, I had a good bit of that.

They don't even know what I have gone through. My mother died. I was abused when I was a child, I was put into care, I saw mother committing suicide, she attempted suicide on various occasions and then she actually succeeded in the end. She died and I witnessed all of that myself she was also an alcoholic, so I've been through a lot.

When I first got depression it was after my third son, my third child, I got postnatal depression at the time. I was living in (UK city) at the time. They took (her son) because I just couldn't cope and I went to see a psychiatrist in (UK city) and he basically said 'oh you're a stupid child, pull yourself together, go and get your child back'. No help whatsoever and I ended up taking an overdose, I just couldn't cope with it. I was sectioned under the mental health act and the result of it all was my husband ended up leaving me. Two weeks after he left me

we came over to tell the family that we were separating while we were on holiday my son was killed. My husband left me in (local) hospital with the clothes on my back, and took custody of my children. So one day I was like a mother and a wife and then I was no-one I was just in a mental hospital with nothing.

3.11.5

Work and/or Training Centres

People talked about the importance for them of work. They found it to be helpful for recovery, becoming well and staying well, and they also found lack of access to work frustrating and stigmatizing. People also talked about the importance of having somewhere to go, to occupy time and meet people, if they didn't have a job, somewhere like a training centre or a day centre.

At least you're doing something, you feel good about it you know, you mightn't work very hard or whatever, but it would be some sort of work and you'd get an extra few bob for it so it would help you, you know. Some of them are well, very capable of getting back to a full weeks work if they got it or go back to it slowly or whatever, you know very capable of doing it.

*I went to Dr*** and she suggested the training centre, like I never really looked back. That's two and a half years ago. I got a job now and all out of it, FAS, it's only a week-on-week-off but it gets me out. My problem is if I wake up in the morning and nothing to do, nothing to look forward to that day, I have to be at something, you know, so I'm getting on*

fairly well now. Hopefully it will keep going like that but I still need to go into the training centre like, you know, to keep my mind occupied, like all the help is there.

People would like to receive more money for the work they do in the centres.

We take in stuff for upholstery we take in tables to be fixed up, chairs, tables to be fixed up. There is a small few pounds to get in the centre for this, could they not spread all that money around the trainees and give them a few pounds extra, give them a few euros extra, like they are doing the work there. You don't get much for what you do. It could be put into a kitty and every three or four months it could be dished out to the trainees.

3.11.6 Experiences of Discrimination and Stigma

People spoke of their experiences of being discriminated against when seeking employment because they were mental health service users. Stigma had a major impact on people's ability to find work or be open about their health status in work.

I used to be with contractors, but I've asked a few contractors around locally and they wouldn't give me employment. One fellow said, he just said, 'do you get paid well out there?' he said, in an ignorant kind of manner. I thought there was an awful lot of ignorance towards mental illness you know, statements like that, a lack of knowledge.

They don't want to know you if you have a mental illness, you know. You've a mental illness and that's it.

...the stigma is there and you're automatically judged if, you know, it says on an application form, do you suffer from psychiatric illness? So I mean, what do you do in that situation? If you say it, well you're automatically judged...and you won't get the job...whereas somebody who hasn't got that background will.

...my boss knows that I have depression but no way would I tell him I have schizophrenia, absolutely no way, he's a very nice and understanding guy and anyone else at work, you don't tell them anything.

3.11.7 Relationships

People spoke about the impact of their mental health difficulties on relationships, and their experiences of illness affecting their ability to create and sustain relationships. There was also discussion of some of the other losses people had experienced, especially peace of mind and trust in their ability to cope with everyday life. This often caused significant fear of relapse and in some cases people felt they'd lost everything.

I always think, the odd time of how would my life be if I didn't get sick, what would I be doing, would I have a wife and kids or good job or my own business or be on the dole or what way I'd be, you know. I suppose there's really no way of telling much but, I think maybe,

you have this illness, most people have a serious illness in life I think, and you see things from a different perspective. It can change your outlook on life in a lot of ways and I suppose, over the years it is kind of, you develop a kind of a way of coping basically.

If you're in a relationship I mean you're going out for a week or so and they find out you have schizophrenia, gone, they dump you, you know, they just don't want to know you, you know what I mean. The fear factor is there like, I don't know.

I got sick, it was a shock to me and I wasn't expecting it, my life was full like, I had my mates and I had, you know, relationships, and all of a sudden it went bang, like that, it was all taken away from me.

3.11.8 Relationships and Stigma

Many comments refer to the impact of stigma on friendships and other significant relationships, and the loneliness of feeling isolated from others due to misunderstandings and fear of mental illness. Stigma resulted in these people feeling judged, lonely, and ashamed and contributed to a feeling of bringing shame on their families as well.

I find it can be a very lonely experience, there's so much stigma attached to mental health, mental illness these days. The stigma is still with us unfortunately but just with the help of our families and friends we can get by, you know, they understand at least. But in general you

know, it's a lonely thing to have an illness, it can be very lonely.

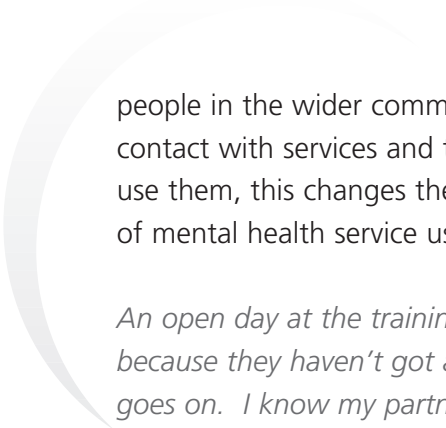
I'm ashamed to mention (specific centre), I'm just afraid to mention it, even to relatives or they'd know where I was, I was in (named institution), but because of this stigma, I'm still living, I suppose I'm still living in the past. What people told me in the past that it was a mental hospital, like you know, and they're all nuts in there, for the birds, that's the way they think.

I know my daughter came to see me in the training centre, you know, when I was there for a couple of years. It was tea break in the dining room and we were all sitting around and I introduced her to everybody, she went out and she was crying her eyes out to think her mum was in a training centre with people with depression and all sorts of things, she just, she couldn't cope with it. And then my family saying to me don't mention that you were an alcoholic, and I do mention it. And they say you're not an alcoholic now and I say I am until the day I die. You know they really sweep it under the carpet.

I always remember one woman saying to me, well it was my ex-mother-in-law, it would be a decent thing if you died, bringing shame on to the family, you're in a nut house, you know, and that was her attitude.

3.11.9 Anti Stigma Measures

Some suggestions were offered to combat stigma and demonstrate that if



people in the wider community have contact with services and the people who use them, this changes their perceptions of mental health service users.

An open day at the training centre because they haven't got a clue what goes on. I know my partner personally when I said I was going to the training centre he had a few words to say about that. But I said 'I am going, I am really enjoying it there.' They do not know what goes on, I said to him, 'You haven't got a clue about the people in there or what goes on in the training centre. You just think oh yeah, what a bunch of nutters they have, but they haven't met us we are human beings, you know what I mean.' Unless they come in and see, you know, that it's not like...It is because when I first went to the training centre I didn't know what to expect. I was shocked I was really surprised at how lovely and nice it was, the people are.

Focus Groups with Carers

4.1 Introduction

A focus group was carried out with carers of people using mental health services. The group had carers from different areas within the HSE Western Region and explored their experiences of partnership with the mental health services. A number of themes emerged from this process, which will be presented and discussed in turn.

4.2 Experiences of Partnership

This focus group had a different perspective on partnership and their experiences with the mental health services. Their complete focus was on the services their children, (they were all parents), did or didn't experience. They articulated their own needs only in relation to support for their family member, who had all been diagnosed with schizophrenia, were all now adults, over 18, but still dependant on the parents.

The overall theme to emerge from this group of carers was isolation, and lack of involvement and support from the mental health services. They had good reports of individuals within the services who had been very helpful and supportive, but the overall experiences did not suggest they felt treated as equals in the care of their family member, nor supported in caring, or accessing support for the needs of their family member. A very difficult issue for people was the decision to sign their

loved one in for treatment and the consequence of this on their relationships.

There was complete consensus in the group, as to their experiences and opinions about contact with the services. The discussion was animated at times as they contributed their common experiences to the process of the focus group, but they never contradicted each other, rather offering complete agreement and examples from their own experiences to support someone else's point.

4.3 Consultation and Involvement

The parents often felt uninvolved by mental health services when their family member needed help. They described frustration and confusion in trying to understand what was going on.

The Health Services aren't proactive, in our experience, they wouldn't come phoning you and saying 'what do you think if?' or 'we're suggesting A, B or C', now that has never happened in our experience.

... it was only through a terrible amount of looking and help, or looking and researching ourselves that we found out that they had some sort of half-way house in town, in Galway, where he could go and we had to go and seek that, it wasn't offered.

If you didn't ask any questions there was very little coming to you and from let's

say early on. I remember once, out of pure frustration when we demanded a meeting with the psychiatrist.... We just demanded to know where we were going and what was happening and all of this kind of thing, and it was only that kind of confrontational situation that things began to open up for us.

Otherwise you're sort of pigeon holed and moved along.... The individuals, the people themselves, I don't think we've ever met anybody that has been anything other than helpful, courteous and all of that sort of thing but the system seems to, very slowly dispense information ... Now that's like something full of holes you know, where you've nothing to stand on but like having experienced it, I can understand that it's true as well because we've seen people, we've seen our own people at different stages and come to the stage where they're an awful lot better today than they were before.

...but you could literally be told well after three or four weekends of coming out on Saturday, going back in on Sunday evening, suddenly well on Thursday, (Son) is going home tomorrow. You have no preparation and this is where we kind of kicked for touch and said hang on a minute we're not ready for this.

4.4 Support from Voluntary Groups

People found they received a lot of information and support from the voluntary sector.

Maybe it's because we've educated ourselves or whatever over the years,

over the three and a half years but I think if I didn't go to the Schizophrenia Ireland meetings, I wouldn't know a lot of what's going on because, it's because you have to go out and fight for the information that should be available.

Before we attended any meeting or we'll say support group, we would have been on our own sort of meeting the doctor in and out of hospital and all of that and then meeting the social worker coming to the house. Like it was all that sort of support but...

People in the group spoke about how important meeting other parents was for them, people who had also experienced the devastating impact of a family member developing a serious mental illness; they found meaningful support from these contacts

We were blessed to meet a couple who went through the same, a very similar experience.

4.5 Communication with Doctors

People had positive and negative comments on their relationships with doctors. Parents appreciated the reason for delaying about diagnosing schizophrenia. However there were also comments displaying a lack of satisfaction regarding communication.

And then when I went to Dr *** the other day they added Lustrin which is an anti-depressant and he was doing all right on it but I thought he was just getting a little bit high, but when we

went it had been three months since the last appointment and she said 'No', she said, 'I think actually I'll up it a little bit' and I was amazed but I said she's the professional, she knows. But then I talked to the nurse afterwards and, the nurse said 'I can't believe that she upped it' and does she realise that he'd been high, you know. And they decided to go back to her and lower it because like he's, she's the consultant, she decides what, when, where and how but yet we got an appointment yesterday (mid July) in the mail for October, that's his next appointment. Do you know what I mean, it's just not good enough.

4.6 'Labelled for Life'

A participant mentioned the significance of a diagnosis on the rest of a person's life and was grateful that their son's psychiatrist was aware and sensitive to this.

...when we were kind of asking what was wrong and what the diagnosis was and all that, the psychiatrist said, which was a very valid point I thought, you know, if I said something today and I write it down and say there's your diagnosis, to say somebody has schizophrenia it's a life sentence that tracks you in a certain way for the rest of your life. You cannot do so many things you know, there are doors closed to you almost from that diagnosis, there's a lifestyle, way of life that you're condemned to...and now an awful lot of it is stigma and all that but an awful lot of it is very real.

4.7 Care Plans

People had no sense that there was a structured approach to dealing with their family member.

After months of wondering where things are going we asked is there a plan here or is this just going from week to week and month to month or whatever, what's the plan? And I was expecting to see something given to me on a bit of paper, there was no plan and then you wonder if there is a plan and it doesn't go right, do they scrap it or where does it go.

4.8 Signing Committal Forms

The issue of having to sign a family member into hospital against their will was a difficult and upsetting experience that many of the participants had gone through, and talked about in the group. They felt strongly that this was unacceptable and damaging to their subsequent relationships with the person.

We brought him to the hospital, I then had to, was confronted with the situation of having to sign the document, even to this day I don't know what would happen would they have sent us all home. As I often say in these situations if it was a heart attack or a stroke you are lifted body and bones and dealt with. If you have a mental illness or mental breakdown there is so many procedures to get help.

He said to me, he said 'why did you put me in it'.

Yeah, 'I wouldn't have been in hospital if you didn't put me in it'.

He was trying to get out, trying to escape so he was trying to get out because he didn't like it. And I can understand you know he just said 'look mum I'm fine, I want to go home' and I had to sign and I hated it, it was all my fault

...my sister had to sign her in you know and she was very, very angry, very upset about that after when she recovered.

If someone is that seriously ill, they could do damage to themselves, to others. There so many things that can go wrong, they can kill themselves you know, they can kill others.., it's so serious, it's so critical, it shouldn't require, I mean it's 2005, you're not going to put someone in a hospital now and forget about them for twenty years, that just isn't going to happen. Thanks be to God now that the walls are down and that we're able to sit and talk about it but the persons themselves needs intervention and help the same as if they fall and break their leg they have to be helped up. And this shouldn't require Guards and all these other things. But if they've a mental problem how can they decide that they need help like? They cannot decide themselves, so that's what I think is wrong.

4.9 Aftercare Support

Carers found that support after hospital was lacking and were often frustrated by the difficulty in securing relevant or consistent support or structures for their

relatives after they left hospital.

You're left then in isolation, ... all of us have met people I think from everywhere and we've all got the same experience, there's no back-up, there's the emergency, the fire brigade to get a person to hospital, get them back on their feet, get them out on the street... There's no follow through for back-up for work, for career, for life and that's where we're all struggling. But there's nothing, well I won't say there's nothing, but we don't know where to go after this.

...but if there was just a place for when you were in between, that you were okay but you're still on medication and that, you're becoming a lot more independent but you still need guidance, where they could do various courses, even just do six weeks of something and do six weeks of another and give them a good taste of various, say trades even, I'm just picking that out because (son)'s interested in doing a trade or carpentry. There's nowhere really, I mean I've tried to find out.

...if there's a course they do a course. Bang, the course ends, it's the wall, you turn around and there's nowhere to go.

That's where we're all struggling. I remember you mentioned the word partnership, you know that's, if we're all in this together, is it only at the emergency stage of where there's help, because this is a life condition.

4.10 Stigma

Stigma has a major impact on how the illness affects everyone, and on the carers' ability to be strong advocates, or to lobby for more resources for the services their relative needs.

Is it because there's such a stigma that we're not fighting? I have put forward my name a hundred times, I will volunteer, I will do whatever, just ask me because I only work two days a week. I don't want to go out waving a flag down Shop Street with Schizophrenia Ireland because then they know ah my son, I thought it was depression he had or something, you know

...our son when he started this job he didn't want them to know that he did have schizophrenia.

...if you walked in to the pub tonight or walked in to work tomorrow morning and say I know someone with schizophrenia, you won't do it. ...You won't sit down at a football match and talk about something like that, it just doesn't happen.

4.10.1 Combating Stigma

The parents felt that stigma should be addressed.

I think information is probably the most important thing, I think there should be information about mental illnesses and schizophrenia introduced at national school level and brought right the whole way through and that would make

people aware, and you educate people that the words aren't frightening, ...because we didn't know anything about it and I had to look up the word psychotic in the dictionary to see what it meant, with our first experience. When the doctor told me I came home and I was told, well I asked what's wrong, a psychotic episode.

If you had some information about that, I mean if they had sex education, they have every other sort of education but mental health is taboo, so...it shouldn't be all confined in to their own little sort of tribal area if you understand me.

4.11 Lack of Resources

This was experienced as a painful reality of the priorities afforded mental health services within the overall health budget. People were very hurt by the unavailability of simple things due to budgetary constraints. Accessing extra resources was made more difficult due to stigma. People spoke of a reluctance to be publicly identified with mental health services.

I think ..that if you take it on to this kind of planning level where you have a committee or a council that's participating, that can do certain things that don't really effect your daily life but the bigger thing would be that it could give a voice to or give support to have funds properly put into the services. ..Because that's one thing that you can see, I mean, we've one lady at our meeting the other night you know, she

was virtually crying that her son was in the psychiatric unit and he said 'no mother, I can't play pool because there's no, there's one ball short' and somebody else said 'you're joking me, it was like that six months ago'.

And I know one nurse said to me it's like banging our heads against the wall, she said, it's the parents if they could cry out more. Then again it's that stigma. I suppose for me as well having to walk around the street with (sign for Schizophrenia Ireland) but maybe I will one day... yeah the facilities and activities ... like pool and, they even have two tables, and it's across from the toilet. I know there's more facilities and resources but that is an issue.

That's indicative of one thing, maybe it's lack of resources but I think it's more important for families to be involved in the care of their person on that level rather than this bigger council thing.

I mean they have spent millions on UCHG, and the last money that was to be spent, it was to be spent on the psychiatric unit and they ran out of money.

I remember my son saying to me when he was ill, we were walking through and he said look dad he says, do you see the frame on the window, it's rotting. He said that roof could fall on me some day when I'm walking down here. And that's just on a very basic level. And it was, you could literally stick your finger through the frame of the window.

4.12 Sectors and Changing Doctors.

The administration structures in mental health services were also commented on. People found the rotation of junior doctors unhelpful, and were frustrated by the division of services into sectors, with the resultant lack of choice.

You can't cross the sectors. It's all islands. It's an island here and it's an island there and some islands are better than others, you know.

...what has been a huge issue as well, the fact you go and you meet one person and then three months later you might meet the same person but three months after that you've a new person and there's a rapport built up with somebody for a period of time.

Discussion

5.1

Introduction

Edwards in his recent book *Partnership Working in Mental Health Care* states that the old model of care acceptable in the past within mental health services, that users can be 'acted upon or treated', has shifted to one with a focus on effective communication, therapeutic relationships and partnership working. This is generally the way of best practice and would ensure that the consequences of using mental health services would be a therapeutic, empowering experience and not one with a negative result or outcome in a person's life. It is also an approach to working with people that implicitly respects their human rights and dignity.

In the context of discussing the two main types of partnership, therapeutic and strategic, the report will describe the main themes emerging from the focus groups, such as communication, care issues like care planning, key workers, medication, aftercare, training centres and respite, and other issues such as relapse and recovery, experts by experience, stigma and employment.

5.2

Therapeutic Partnerships

Therapeutic partnerships, for the purpose of this study, are regarded as the relationships between individuals, service users, carers and providers, which are focused on a therapeutic outcome, including a recovery focus. By their nature these will include the quality of the relationships and the communication styles between the people involved, how

people perceive equality and how issues such as power and control are negotiated. Respectful and dignified interactions between people can be a measure of whether a therapeutic partnership is present. Therapeutic partnerships are important in supporting the process of recovery of people using the services, as relating to people in this manner would be important to re-building the damage to their self-esteem which is a consequence of mental health difficulties. It is disappointing, however, that there is little evidence of therapeutic partnerships in the accounts given during the focus groups. Instead, many obstacles to partnerships appear to be present given these findings. The values and beliefs that underpin therapeutic partnerships should be a core principle of service provision and an explicit element of the care planning process.

5.3

Communication

There is evidence of poor communication. Service users describe not feeling listened to, or not feeling engaged with members of staff, especially during times when they might be feeling low or suicidal and actively needing this support. Carers also expressed a lack of satisfaction about communication. This lack of communication skills is one main reason why therapeutic partnerships cannot be said to be prevalent throughout the mental health services. There is no evidence of a healthy communication culture in the mental health system. A work situation that is 'too busy' for people to talk with staff is not

appropriate if it inhibits communication. The lack of an explicit culture which fosters communication skills is a serious obstacle to developing partnerships. There appeared to be a lack of consistency in the quality of communication received from staff. Communication should be a fundamental service skill for all staff. Staff need to understand the importance of good communication and its impact on the service users and carers. This could be achieved by developing a communication culture within mental health services. An effective system to facilitate good communication should be developed.

Communication ability can be significantly affected by mental distress. Another issue that therefore needs to be addressed is that service users may need help in communicating with staff. If people are not used to speaking up and asking for help, it may be difficult for them to make their needs known. This supports the need to develop the systems of communication between staff, service users and carers.

However a mental health service is to be evaluated, communication skills are fundamental. If the people receiving the service do not experience effective, emphatic communication, then urgent attention must be given to addressing this deficiency.

5.4 Relationships

Relationships with staff are very important for service users, many of whom may feel both vulnerable and isolated due to becoming dependent on mental health services. People reported very differing experiences in interacting with their doctors, with one common conclusion: this is a vital relationship over which they feel little or no control. Due to the way services are delivered on a sector basis there is no choice about either the consultant psychiatrist or the entire multidisciplinary team that works with the individual, yet this relationship with their doctor is a crucial one, if the individual is to have a therapeutic partnership with staff in the mental health services.

Staff attitudes and behaviour are significant factors influencing communication and have in some cases contributed to an ethos where dignity and respect are not an essential component of the workplace. This lack of a culture of respect may have allowed some of the reported instances of abuse to occur. Dignity, respect and equality should be maintained in any relationship between health professionals and service users. This should be the cornerstone of delivery of mental health services. This could be achieved by incorporating this principle into the vision statement for services and building it into the service planning process. A user-friendly system for dealing with breaches of dignity and respect would also be important. This highlights the necessity of having easy-to-access complaints procedures and systems for customer feedback.

5.5. Care Issues

5.5.1 Care Plans

Care planning can be regarded as a crucial aspect of providing mental health care. It is also an area where there is significant scope for partnership as it an opportunity for the service user, service provider and carer to become involved in the care process.

In developing care plans, *A Vision for Change, (DOHC 2006)*, states 'The needs of each service user should be discussed jointly by the team, in consultation with users and carers, in order to construct a comprehensive care plan. Care plans should be written and agreed between all parties, and include a time frame, goals and aims of the user, the strategies and resources to achieve these outcomes, and clear criteria for assessing outcome and user satisfaction.'

Most of the accounts given demonstrate that participants did not feel sufficiently engaged to be able to experience partnership, therapeutic or strategic. If people do not believe they are being listened to, being consulted about their experiences, then partnership is not a reality for them. If people do not believe they are heard about how the illness or mental health difficulties impact on and impoverish their own or their relatives' lives, then they will not believe that they are being treated as equals and consulted in the development of their own care plans. If care planning is not a meaningful and consultative process for

service users and families, either during an admission to an acute unit, or on discharge, in planning their aftercare, then individual needs assessments and plans to meet these needs are not being adequately conducted.

This study highlights the need for the care planning recommendations in *A Vision for Change, (DOHC 2006)*, to be addressed. An action plan needs to be developed for the HSE Western Area, utilizing a partnership approach, to ensure that this is achieved in a timely and effective manner.

5.5.2 Key Workers

Another aspect of care that was discussed in the groups was the importance of people's relationships with their key workers: that is, if they had one. Here participants also had varied experiences. Some people had worked with and had access to a key worker, but others had no key worker. The lack of a key worker for these individuals was a significant issue, and it appeared to have a negative impact on their relationship with mental health services. All service users should be allocated a key worker and the therapeutic benefits of this relationship should be regularly reviewed.

A Vision for Change, (DOHC 2006), states in relation to this aspect of care, 'Where care of an individual is assigned to more than one of the team members, a 'key worker' – a team member who will be known and accessible to the service user and through whom clinical services can be personalized and coordinated –

should be identified.’ Once that principle is adopted by the service providers then issues around building therapeutic partnerships can be explored by the key workers.

5.5.3 Medication

For many people medication is the main treatment offered (Brosnan et al 2002) yet this study found service users were not routinely consulted about this aspect of their care or treatment. Therapeutic partnerships may be difficult without service users having a sense of control over this aspect of their lives. ‘For medication to be tailored to the needs and lifestyle of an individual, that person must play an active part in decisions about which drug is taken, not to mention how much, when and in what form’(Repper & Perkins 2003). Consultation about medication must be incorporated into the care planning process to ensure consultation about medication takes place.

5.5.4 Aftercare

Both users and carers expressed a major difficulty with aspects of aftercare, including finding adequate supports or a placement after leaving hospital. The importance of having work or structure to their days was emphasized. All felt that this is currently a lack in the service when discharged. For some people day centres addressed this need, but many others did not find these centres adequate for their needs. Training needs for young people with a recent diagnosis of schizophrenia are not addressed, much

to the frustration and distress of their families. If there is no appropriate place to move on to following discharge from an acute unit, the serious consequences of experiencing mental health difficulties, such as damaged relationships with family including siblings, loss of peer networks and education or employment opportunities, are hugely exacerbated. These findings highlight the need for community based services, and support the move towards this model currently being adopted by mental health services.

5.5.5 Training Centres

Many of the participants attended training centres and found that they were supportive and addressed their needs in terms of having social support and a structured way to pass the time. They felt more in control while attending such centres and felt included somewhat in planning the activities available. For some people they were helpful in gaining access to part-time work or sheltered work. However they were also perceived as being difficult to move on from. Training centres should be a means to an end, not an end in themselves. The need for training centres to help individuals ‘move on’ and take up a more active role in their community should be reviewed. Another issue raised by service users was the low financial allowances received for work done. Allowances should reflect the value of the work undertaken and the HSE should take this into consideration when determining allowance levels.

5.5.6 Respite

Another specific topic discussed at some length by different groups is the need for respite and other supports people may need while experiencing a crisis in the community. Having somewhere secure and safe to go could alleviate the need for visits to Accident and Emergency Units, and indeed admission to Acute Units. Some respite facilities are available in the HSE area (e.g. Ashbrook House, Mayo Mental Health Service). However it is unclear whether there is sufficient overall service to meet the needs of service users, as this study indicates that having somewhere to go in 'in a crisis' is an unmet need. Appropriate respite facilities should be a specific component of the HSE's move toward community based mental health services.

5.6 Relapse and Recovery

For many service users there is an expectation that they will experience recurrent episodes of ill health. This specific fear was mentioned by people in each group. This has major implications for people, because in the past a diagnosis of a major mental illness was a life sentence. Expectations of leading a normal life were shattered and the 'revolving door' of frequent readmission became a reality for many service users.

The recovery paradigm sees a person's progress through their journey as a series of stages, moving through differing levels of wellness, and includes recognition that setbacks happen and are a natural part of the process (Repper & Perkins 2003). This

approach has gained momentum within mental health policy and practice in the UK, North America, Australia and New Zealand (Repper & Perkins 2003). The development of the recovery paradigm within mental health services offers a new approach to this issue. It places the breakdown of mental health into the context of an individual's everyday life, makes sense of the process, and offers hope and optimism for the future.

A key element of the recovery process is a connection that supports the individual in their recovery. A therapeutic partnership would provide certain conditions that help maintain the movement towards wellness, including good communication, respecting the other and allowing them to take responsibility for their own recovery. This approach needs to be integral to service delivery ethos so that it is an attitude that permeates every interaction between the staff and recipient of the service, user or carer. This should help prevent readmission and relapse.

The importance of recovery has been highlighted by the Mental Health Commission (MHC 2006) who have produced a paper to promote discussion of the concept, *A Vision for a Recovery Model in Irish Mental Health Services*. If recovery is to be embedded into service delivery, there will be a need to provide training in the principles of recovery, as this approach has not yet been incorporated into the organisation and delivery of services (MHC 2006). The Western Alliance for Mental Health is currently in the process of developing a

training workshop on the recovery paradigm. Similar training initiatives should be developed and delivered to all mental health services in the region.

5.7 Experts by Experience

The person who is going through an experience is by definition the expert on how that experience is affecting them. They are best placed to say how they are responding to medication, how they may be experiencing side effects or how a particular aspect of their care is suiting their needs. However, the degree to which people were asked by health professionals about what helped them to stay well is unclear.

Service users who have regained a level of stability within their lives and are engaged in the recovery process have a wealth of experience to offer. This valuable role has been acknowledged in other areas. Some services are now creating a role within multidisciplinary teams for someone with this perspective (Perkins 1998). This experience is already informally available to people within the services and many accounts were present of people offering support to each other, in all the groups, including the carers group. This support from a peer group is invaluable because it offers that unique perspective and understanding that is shared by people who have gone through a similar experience. A number of support groups are currently available in the region. These should be actively promoted by health services to ensure that service users and carers can access this support.

5.8 Stigma

The impact of stigma was a common theme for users and carers.

Discrimination experienced by people as a result of mental health difficulties has a major negative effect on people's lives. For example it inhibited many service users from seeking work and carers from lobbying publicly for improved services or resources. It has a profound impact on how people feel about themselves, on their relationships with others and on their ability to find meaningful work. This discrimination by its very nature devastates the sense of self already damaged by the illness and by contact with the services. Often the consequences for carers of being publicly active and thus identifiable by association with the mental health services in the eyes of neighbours or acquaintances, were too negative or unacceptable to their adult family member affected by the illness.

There is some evidence of attempts by certain training centres or day centres to address stigma in their area by inviting local people in for open days, or inviting partners and family members in to visit a centre. Evidence that this can be effective was offered by participants from their own experiences. It is not a widespread practice however.

Stigma and discrimination are issues of great concern to family members. They felt strongly that a lot of work needs to be done to educate the public about issues relating to mental health and prevention of mental ill health. Many

people spoke of the need to start early in schools to break down the culture of stigma and negative stereotypes around mental illnesses. There is a need to create a cultural climate where discussion of issues to do with mental health is widespread and commonplace, where mental health is no different to physical health, where a breakdown is not usually a cause of shame and embarrassment, but just an situation which requires attention from medical or other experts.

Whilst the issue of stigma is often highlighted, actions to tackle it are somewhat limited particularly in an Irish context. In *A Vision for Change*, (DOHC 2006) actions to tackle stigma were limited to three broad topics, with no specific areas of action identified. Particular actions to tackle stigma need to be developed. Evidence has shown that the most powerful way to tackle stigma is by utilising the skills of those who have experienced its negative effects (Corrigan & Lundin 2001). This should form the key component of any initiative to combat stigma.

5.9 Employment

Employment is a key issue for services users and a major obstacle to achieving meaningful integration into society. There are many barriers to accessing employment and yet the value of appropriate employment is recognized in helping people recover their self-esteem and stay well (Brosnan et al 2002). Training centres and sheltered workshops have formed the main interventions

offered. However, as stated earlier, there are difficulties in 'moving on' into meaningful employment. Recent research suggests that different approaches can be effective, (Bond et al 1997, 2001 and Crowther et al 2001); for example in helping the person to get the job and then providing support on the job, and giving attention to an individual's preferences for the type of employment they would like. The feasibility of these approaches should be investigated.

5.10 Support from the Voluntary Groups

Participants reported receiving support from the voluntary groups which they found to be very helpful. For many this filled a need unmet by the statutory sector. The support included information and education on different aspects of mental health difficulties but also peer support, the support of others who either were affected by the same conditions, or had gone through the same process of seeking help and information. The emphasis placed on recovery by some of the support groups was helpful for families and individuals affected by mental health difficulties and offered hope in the challenging period of trying to understand and come to terms with a new diagnosis. Some of the users also spoke of the support available from meeting with other people who had been through and were living with similar experiences, as distinct from generic groups of people with all kinds of difficulties. The value of peer support was clear from the accounts within the focus groups.

People reported experiencing partnerships through their contact with voluntary organisations. This highlights the vital role that voluntary organisations play in mental health service delivery. There is evidence to suggest however, that the statutory agencies are not recognizing voluntary agencies as partners in care (Brosnan 2005). The contribution of voluntary groups should be recognized and capitalized on by the statutory organisations through a partnership approach.

5.11 Strategic Partnerships

Strategic partnerships involve the inclusion of users and carers in forming a long-term plan to achieve a specific purpose beyond individual needs, such as improving services. From our study there was no evidence that either service users or carers felt involved in any strategic partnerships with mental health service providers, or consulted about any service developments or planning. The priority for carers was immediate care as opposed to strategic partnerships for service development. Fear of criticizing the services, and the stigma attached to involvement, were also factors. Service users do not feel involved at any level except for their own individual relationships with staff, apart from the few who had been involved in specific projects, e.g. Cruinniú, Pathways, Clubhouses.

There is a clear need for strategic partnerships to be developed at local, regional and national levels of mental health services. This is supported by

A Vision for Change, (DOHC 2006), which recommends peer-provided mental health services and the inclusion of people who use services on local catchment area management teams as well as the establishment of a national service user executive.

In the UK both health and social services have developed strategic partnerships. For example, in Northern Ireland service users have been involved in staff recruitment and employed on community assertive outreach teams. (North & West Belfast Health & Social Service Trust, 2005). This approach is clearly the way forward if services are to be responsive to the needs of those utilizing them. There are indications that this is beginning to happen throughout the HSE, for example through the inclusion of the Irish Advocacy Network at different levels of service planning and development. Currently, peer advocates are providing support and a listening ear to people in many service centres throughout the region. Peer advocates are also participating in the work of different committees within the region and therefore representing a service user perspective. However the presence of an advocacy service, while a welcome development, is not a substitute for a real commitment to involve service users in a truly representative fashion in meaningful and effective strategic partnerships. A commitment to consulting service users and carers in order to 'proof' policy statements and service guidelines for users, similar to the concept of 'equality proofing' which ensures policies are in line with requirements of equality

legislation, is a basic measure which could be adopted. Such a policy could contribute to an ethos that would ensure that service users are included automatically as strategic partners in developing the future directions of mental health services.

In developing such strategic partnerships with service users and relatives within mental health services it is suggested that the strategic partnership guidelines be utilized (NDA 2005). This will help to ensure that strategic partnerships are successful in achieving their objectives by incorporating best practice principles.

Conclusion and Recommendations

This report has explored the two main types of partnership, therapeutic and strategic, and reported on people's experiences of key themes such as communication and care issues, such as care planning, key workers, medication, aftercare, training centres and respite. It also looked at topics such as relapse and recovery, experts by experience, stigma and employment.

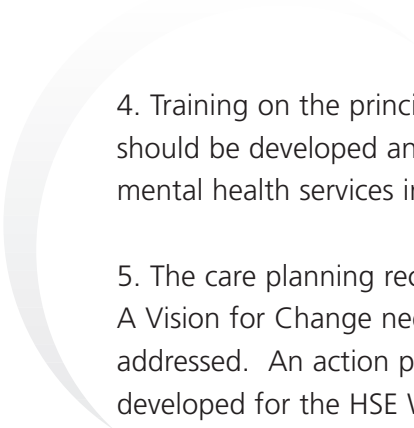
Many issues have arisen from the findings. There is a lack of evidence of partnership working, of the 'partnership interface', or in other words the person-to-person relationship, in spite of many policy recommendations. Equally there is very little evidence of strategic partnerships.

Partnerships between the people who deliver services and those who receive

them is accepted as a key element in working to achieve the aims of agencies such as the HSE Western Area, the Department of Health and Children, and the Mental Health Commission. There is a need to work towards developing practices that foster such relationships and allow them to flourish, both between individuals at a therapeutic level and at a more strategic level. Steps need to be taken to create the environment or culture where this can happen. We offer the following recommendations to facilitate the partnership process within the mental health services.

6.1 Recommendations

1. Strategic partnerships should be developed at local, regional and national levels of the mental health services. These partnerships should be developed using the National Disability Authority strategic partnership guide.
2. Mental health service provision should include the concept of therapeutic partnership as a core component and be an explicit element of the care planning process.
3. Dignity, respect and equality should be the cornerstone of delivery of mental health services. These values should be incorporated into a vision statement for the services within the reformed HSE structures and built into the service planning process.



4. Training on the principles of recovery should be developed and delivered to all mental health services in the region.

5. The care planning recommendations in A Vision for Change need to be addressed. An action plan needs to be developed for the HSE Western Area using a partnership approach to ensure that this is achieved in a timely and effective manner.

6. Systems to facilitate communication between staff, service users and all those involved with their care to be developed.

7. All mental health service users should be allocated a key worker and the therapeutic benefits of this relationship to be regularly reviewed.

8. Respite facilities should be a specific component of the HSE's move toward community based mental health services.

9. Actions to tackle stigma need to be developed and prioritized. Service user involvement must be a key component of these initiatives.

10. The role of voluntary mental health organisations and support groups should be recognized and actively promoted by mental health service staff to ensure that service users and carers can access this support.

11. The feasibility of developing alternative approaches to placing mental health service users in employment should be investigated.

12. The need for training centres to help individuals 'move on' and take up a more active role in their community should be reviewed

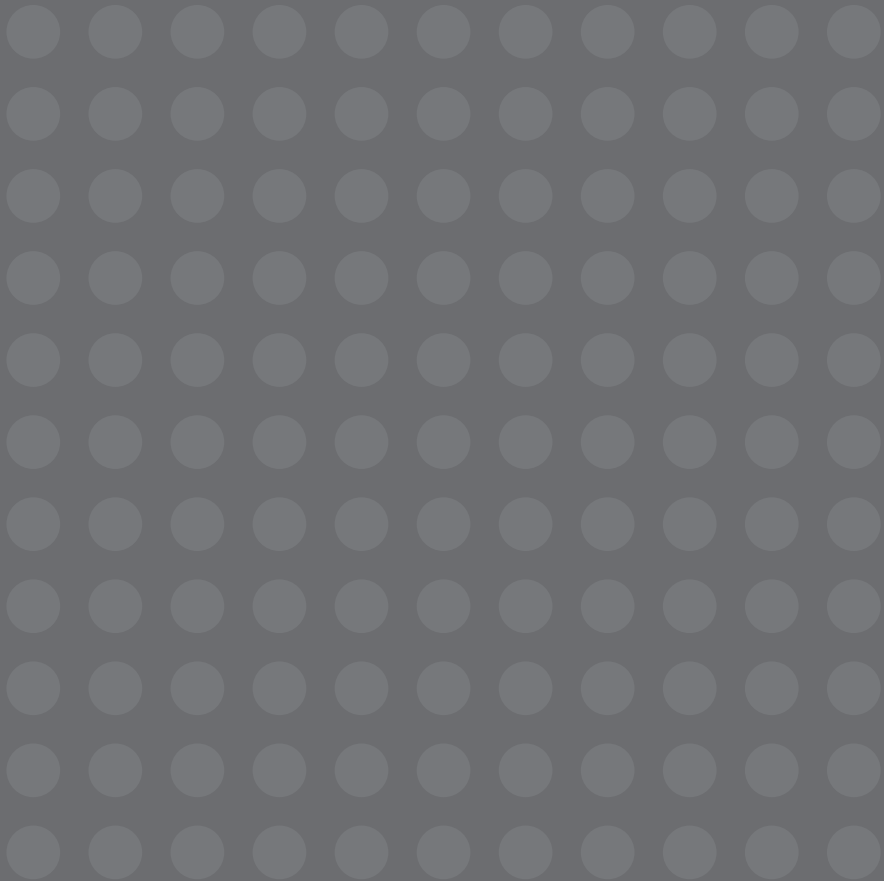
13. Training centre allowances should be set at a level to reflect the value of the work undertaken.

14. Efforts should be made to ensure that complaint procedures and systems for customer feedback should be user-friendly and easy to access by both service users and carers.

It is hoped that these recommendations will be used to develop an action plan for the HSE Western Area, utilizing a partnership approach, to ensure that these changes are achieved in a timely and effective manner.

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ISBN 1 898098 81