Inspectorate of Mental Health Services

National Overview Meeting

Service Users, Carers, Family Representatives, Consumer Panels and Advocacy Groups

3 December 2013

INTRODUCTION

The Inspectorate of Mental Health Services is committed to the active participation and inclusion of service users, carers/family representatives, consumer panels and advocates in the inspection process. To this end, the Inspectorate met with service users and peer advocates as part of its inspection process of mental health facilities around the country.

In addition, in 2013, the Inspectorate sent out an invitation to representatives of service users, advocacy groups, carer/family representatives and consumer panels from around the country, to attend a meeting in Dublin on 3 December 2013. The purpose of the meeting was to acknowledge and put on record their views on the current status of the mental health services and to identify areas for improvement.

This was the fourth National Overview meeting of Inspectorate of Mental Health Services with service users, carers, family representatives, consumer panels and advocacy groups.

Thirty seven people attended the meeting representing service users from a number of representative groups. A list of these groups is set out in the Appendix.

FOCUS TOPICS

1. Service User experience of Individual Care Plans, Multidisciplinary Teams (MDTs) and the Key Worker System.
2. What needs to change?
3. How are service users, carers/family representatives, advocacy groups and consumer panels currently involved in mental health services?
4. What does Recovery mean to you and what has been your experience of it?
5. Any other issues.

The meeting attendees were asked to discuss the above topics in focus groups at the meeting. Feedback was received from each group and an open discussion followed. A summary of the main points arising under each focus topic is given below.

1. Service User experience of Individual Care Plans, Multidisciplinary Teams and the Key Worker System

Individual Care Plans

- It was noted in the feedback from attendees from the Kilkenny and Carlow area that they haven't really seen any individual care plans in their area.

- "Information on a care plan can be quite reassuring and grounding".

- "Some care plans consisted of take X amount of Y medication".

- "Care plans should include outreach to engage with people to assist with taking medication as nobody gains if a person lacks insight and doesn't take their medication. Outreach itself should normally be by agreement".

- "It would be useful to have an individual care plan template. Sometimes people don't know what should actually be in an individual care plan".

- "In some cases there is a lack of discussion, support. The care plan is never mentioned in some cases. Feel there is no Regulation on it. Key nurses changed every day and then there is no continuity which was not helpful. Social workers make very good key workers".

- A service user suggested that a care plan be written in plain English so people can understand it.

- "Care planning should take capacity, will, preferences and needs into account; it should be able to plan around refusal to take medication".

- "Individual care plans can bring pressure for patients who are very acutely unwell. This can cause resentment. Individual care plans focus too much on the deficits and not enough on positives and achievements. Individual care plans should focus on strengths not weaknesses and be goal-"oriented with achievable goals that boost self-esteem".

- "There is a variation in experience of multidisciplinary care planning, in some areas it is aspirational and in other areas it can be effective".

- Service users often ask "What is a care plan and who are on the MDT teams?". One service user stated that a care plan was never mentioned to them. Lack of clarity among service users as to what a plan, a key worker or a multidisciplinary team are.

- "Service users are often told when they ask about their individual care plan that it is there on the board".

- "Service users don't know who are members of their MDT; there are no introductions or engagement".

- "The information should be shown to and explained to service users".

- "Families are not always involved. The care planning process was mostly clinically based and is not holistic in nature".

- "Some service users are not interested in a care plan as it is not written by them, seems to focus on weaknesses rather than strengths".

- "Terminology of care plans can be off putting".

- "There is pressure on services, the Mental Health Commission wants individual care plans in place, then it just becomes a requirement and paper exercise for the service. The care plan may end up sitting on a shelf".

- "MDT team case conferences can be very intimidating and not engaging for service users. Service users feel like an exhibit. Sometimes it can be useful for services users to give their full story. Sometimes case conferences are imposed on service users".

- "Families are not being involved due to a confidentiality wall. Certain insights from family members are not taken on board which may be helpful to the overall care and treatment of the service user".

- Positive success stories for two service users were noted in the Kilkenny area. It was noted that Kilkenny representatives were pleased with the Home Based Treatment Team in their area. They felt that home based care was a way for a family to learn, and it was less isolating for service users as friends and family could call to the person's house.

Multidisciplinary Team Working and Key Working

- Attendees felt that key working wasn't happening enough.

- "The key worker system was quite haphazard".

- "Family members needed to be involved in the key working process".

- "In some cases, key working doesn't make a lot of sense to people. Any person that is there to help someone should be considered a key worker. Lack of continuity is a problem in relation to key working. Inconsistency in the way services are being delivered is also a problem".

- "Multidisciplinary team interpersonal relationships can be difficult. The bigger the void between the service and service user the less effective the result on care and treatment".

Lack of Activities

- Attendees outlined that, in some services, there were no recreation activities or therapies in the unit. Particularly at weekends, there is nothing available for service users. Usually, the television will be on showing a match and not all service users would want to watch a match. There was no occupational therapy. There was a suggestion to have three separate rooms for different activities to give an element of choice to service users.

Medication

- Suggestion to use another modality which is not totally dependent on medication "e.g. in Finland, they have model 'Dialogue system'". Information on medication is not given routinely to service users. Psychiatrists should inform their patients fully of the entire range of effects of psychiatric drugs. There should be a review of the effectiveness of medications as some service users are on the same medications for 20 years.

2. What needs to change?

- "The power imbalance needs to change between the providers of the care and treatment and the service user. Service user's autonomy often forgotten. The use of the Finnish 'Open Dialogue' model might be helpful in this context".

- "The provision of choice to service users would help to improve change".

- "Does a person have to be in crisis to receive treatment?".

- As regards training, it was felt by attendees that it would be beneficial if training in relation to dealing with people in crisis be offered to professionals outside of

the mental health services, for example, gardaí in Templemore, particularly in relation to dealing with service users and families.

- "Service users should have access to help from earlier stages, not just when they were acutely distressed".

- "The idea of a one stop care centres where everything is centralised".

- "There were recruitment issues with Home Base Treatment Teams as staff lost to retirement had not been replaced".

- "In some cases, there was lack of information for service users on medication, diagnosis and side effects".

- "More therapies and activities for service users in units are needed as in some areas there is not much happening on units for service users".

- "Apart from psychiatry, equal emphasis should be given to psychology-based services and talking therapies".

- "There is a fear of making a complaint as service users feel it may have a negative impact on their own treatment. The service provider could be a beneficiary of the service user voice".

- "Many service users felt pressure to take medication even if they did not wish to".

- "The complaints system needs to change. The person that you need to complain to is often the person responsible for some aspect of your care".

- "Service users should be active participants and not observers in their own care".

- "There should be more service user involvement".

- "Multidisciplinary teams to be fully staffed and resourced".

- "A service user should have the ability to request a change of key worker if necessary".

3. How are service users, carers, family representatives, advocacy groups and consumer panels currently involved in mental health services?

There is a lot of service user involvement in Kilkenny in area. For example, the Kilkenny Consumer Panel is involved in governance, policy decisions, care planning and in-patient meetings. There are other elements too including:

- The Kilkenny Voluntary Group which supports family members in crisis and referrals from home based treatment team.

- A Family Carers' Support Group.

- A community based 'Hearing Voices' group (such groups had started in Dublin in Hill Street Family Resource Centre in February 2013). This community group model could be extended.

- Advocacy groups are involved with mental health reform.

In other areas around the country, service user involvement is very fragmented and some areas are not interested in service user views. These difficulties were reflected in the following views.

- "There is significant resistance to service user involvement in some areas".

- "Feel treated like a failed human being".

- "HSE levels of engagement are variable for service user involvement".

- "Getting family involved is important".

- "Establishing consumer panels is challenging in some areas".

- "There are employment issues for service users".

- "Expenses for service users when involved in management teams should be in place".

- "The Irish Advocacy Network provides peer advocacy in approved centres".

- Concern was expressed that patient confidentiality and multidisciplinary teams can offer a pretext for excluding family/friends from decision making.

4. What does Recovery mean to you and what has been your experience of it?

- "Finding your voice is an important part of recovery and leads to service user empowerment. In this context, 'Open Dialogue' and 'Trialogue' can be valuable. Critical service user groupings also have a role to play here".

- "'Recovery from what' depends on the individual and their experience and diagnosis".

- "Recovery should not be so broadly defined; it depends on the individual and the diagnosis. The patient themselves know best what recovery is".

- "Recovery needs to be open-ended to each person and as much input taken as possible from the service user him or herself. All of the services need to come together and be included in Recovery. Recovery should include family members where appropriate e.g. family can give important information in relation to the person. Where family input is important, the use of the 'Open Dialogue' model could facilitate the service user in deciding who they would like to contribute".

- "For some Recovery does mean medication but there should be alternatives such as psychotherapy and referral to peer support groups".

- "Quality of life is important".

- "Service users don't what Recovery means; it is just a term that they have heard".

- "If you are fortunate to meet the right people, then, Recovery is possible".

- "As a term, Recovery could be used as an administrative convenience to move patients".

- "The use of correct terminology is crucial. 'Recovery' is not a good word as it implies digging something up that should best be left buried. 'Discovery' might be a better term as it implies finding new ways of doing things".

- "There is no clarity on what Recovery actually means. For example, it can include elements such as WRAP and mindfulness or, in other words, the approach needs to be holistic".

- "There is a need to be sensitive to people's social status and their requirement to take medications".

- "There should be ways to help people get back into the work force and to resume active citizenship".

- There was concern about: "Who cares for carers in the Recovery process?".

- "Communications need to be meaningful, honest and open".

- "Recovery implies a linear process – however, this is not always the case".

- "Optimism is crucial".

- "People shouldn't be forced".

- "There should be some positive risk taking. In some ways, services are afraid to take risks and say that's the way we have always done things here".

- "There is a need for a Carers' Charter".

- "Physical health issues need to be addressed".

- "Public speaking initiatives would be helpful to empower service users".

- "It is concerning that children are still being admitted to adult units."

5. Any other issues

- "The coercive power of psychiatry has to change. There is no accountability. Health care professionals are too afraid to speak up because of the deference shown to psychiatry".

- "An acutely ill patient should only be dealt with by staff members who can exercise calm. Dealing with such a patient in this way can prevent escalation".

- "The practice of relocating service users further from their families and community just for the sake of closing a mental health service continues".

- "When you dial the emergency number 999, a person should be able to request to get directly to medical services specifically dealing with mental health".

- "When a patient goes home for a few days on leave from hospital their bed may gone on their return".

- "There were no repercussions for breaches of the Regulations. The Inspectorate clarified that their role was to report on breaches but it was the Commission that enforced them".

- "Patients are not informed about the '24 hour holding law' invoked by health services when a voluntary patient tries to leave. In such circumstances, there is no real difference between voluntary and involuntary patients. Trust between a

service user and service provider breaks down when they are not allowed leave. This disempowers patients".

- "The time taken by nursing staff to fill in forms and keep the paper trail up to date impedes on their ability to engage with patients and discuss what is going on in their lives".

- "There should be more liaison between addiction counsellors and mental health services. Service users may fall between the cracks".

- "There should be consistency in providing treatment to service users. A lot of service users see different psychiatrists or therapists each time which is not helpful for continuity of care and treatment".

Appendix

Service user representatives:

Grassroots

Wicklow Mental Health

Tallaght Trialogue

Carers' representatives:

Ballyfermot and Lucan Carers' Group

Carers' Association, Dublin

Carlow Carers' Group

Central Mental Hospital Carers' Group

St James's Hospital Carers

Family representatives and representatives of Consumer Panels:

Cork

Dublin, North City

Kilkenny

Limerick

Advocacy Groups:

Irish Advocacy Network

Kerry Mental Health Association

Mental Health Ireland

Mental Health Reform

National Service User Executive (NSUE)