Inspectorate of Mental Health Services

National Overview Meeting for Service User, Carer/Family Representatives, Advocacy Groups and Consumer Panels, 2012

Introduction

The Inspectorate of Mental Health Services is committed to the active participation and inclusion of service users, carers/family representatives 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 October 2012, the Inspectorate sent out a letter of invitation to representatives of service users, advocacy services, carer/family representatives and consumer panels from around the country, to attend a meeting in the Mental Health Commission offices. 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.

31 people attended the meeting representing the following – Irish Advocacy Network (IAN), the National Service User Executive (NSUE), Kilkenny Consumer Panel, Consumer Panel South East, PROTECT (employed mental health service users) St Joseph's Association for Intellectual Disability, Whitehall Carers Group, SHINE, Mayo Consumer Panel, Carlow Consumer Panel, St James Hospital Service User Group, Consumer Panel Limerick and Mental Health Reform.

Focus Topics

1. How are service users, carers, family, advocacy groups and consumer panels currently involved in mental health services?
2. Are there regional differences?
3. Give an example of an ideal service.
4. Give an example of a poor service.
5. What needs to change?
6. Definition of Recovery and how to transmit to clinical teams.
7. What are the effects of reduced resources?

An open discussion followed and a summary of the main comments arising under these headings is presented below:

How are services users, carers, family representatives, advocacy groups and consumer panels currently involved in Mental Health Services?

- Active consumer panels in areas such as Waterford/Wexford, Kilkenny, West Cork, St James Hospital, Dublin and St Patrick's Hospital Dublin. These consumer panels met on a regular basis with management.
- In other areas Consumer panels had been formed but had not got off the ground yet e.g. - North Dublin.
- Support groups such as Shine, Aware, Bodywise, around the country and specific support groups such as Eolas (North Kildare), Protect (Wicklow), Sli Eile (Limerick) and Endeavour program (West Cork), Ship program (Wexford) Prosper project (Mayo).
- Paid service user post on community mental health team in Wicklow, Sligo and Cork (Genio funded).
- Community Partnership funded projects such as Gateway in Rathmines.
- The Irish Advocacy Network (IAN) met regularly with inpatients and fed their needs back to management and in annual reports to Mental Health Commission (MHC).
- Some HSE clinical governance committees had a service user and/or carer representative on them.
- Examples were given of activities (art classes, gardening in the grounds of the hospital etc) however there were not enough of these.
- The key was to establish "buy-in" from a wide range of staff from Consultants and Nurses all the way to security staff – Need to engage staff and convince them to listen.
- Importance of communication – Make sure carers and Advocacy groups are well aware of any upcoming meetings, seminars and other opportunities to get involved.
- A representative for Intellectual Disability Services pointed out the MHC reports provided useful guidelines for meetings with hospital staff often highlighting issues missed by groups.
- Service User groups were important as they created consensus on what the issues were.
- Benefits of social evenings organised by service user groups.

- The need for wider consultation was pointed out – Advocacy often worked according to protocols and was therefore not the answer to everything.
- Service User Groups needed to be aware of where they fitted into A Vision for Change which would give them greater power/influence.
- A question was posed as to whether or not it would be beneficial for Service User groups to come together and form a single voice.

Regional differences

- A representative for carers in North Dublin said that their involvement was quite “patchy” and suggested that the HSE should provide an administrator to assist with the administration of the carer network to streamline processes.
- A representative of Kildare carers also described their involvement as “patchy”.
- Carlow Consumer Panel reported a particularly negative experience.
- Broad consensus that panels in Kilkenny enjoyed particularly good relations (see example of ideal service)
- Disparity in experience was because of disparity in the dominant culture of a particular hospital/mental health service.
- Even within an area there were differences in the quality of service and attitudes towards service user /carer involvement e.g. Carlow and Kilkenny.
- “Every area had its own vision of A Vision for Change”
- It seemed to be a big lottery around the country as to how well staffed multidisciplinary teams were.
- Some areas much better than others in making link with community services e.g. West Cork.

Examples of an ideal service

- Panels and groups in Kilkenny reported a high level of inclusion and satisfaction.
- Community services in Cabra – Focused not just on service users but their families as a whole and followed up with these patients. It was pointed out however that more resources were required for them to make home visits.
- An example of a Cork based service named Endeavour was given which focused on cases of self harm and believes certain people will never be suited to admission into an institution.

- Some service users reported that they felt the attitude towards them was slowly changing towards a partnership approach.
- Service user involvement on Community Mental health team was really making a difference.
- Some community mental health teams (e.g. New Ross and Cabra) “really making a difference to my recovery”.
- Individual care planning had improved in many areas.
- The Inspectorate’s report could be very helpful at encouraging improvements in services e.g. use of Individual Care Plans.

Examples of a poor service

- Some consumer panels reported little contact with management; management were invited but never attended meetings.
- Some consumer panels reported little say in clinical governance.
- Suggestion that “middle management” in some mental health services was responsible for resistance to change.
- A service user reported dissatisfaction with transfer of patients from one area to another, which caused a disruption in the relationships between staff and service user.
- A service user reported a “culture of disrespect” among staff in one hospital. Dehumanizing experience, consultants made all decisions, problems with making a complaint, staff talked on phone during session.
- Lack of meaningful activities in some centers, boredom an issue.
- Service users still afraid to complain in some areas, particularly if they were involuntarily detained.
- Many clients felt there was still too much emphasis on medication and not enough on talking and occupational therapies.
- At Tribunal service user was not allowed to speak.
- Being “nursed” in pyjamas was still an issue in some units.
- Still very limited out-patient and community services in many areas.

What needs to change

- Not enough of our overall health budget is being spent on Mental Health Services.
- Tendency for public psychiatrists to dismiss service user concerns as paranoia –“social workers should step in”.
- Make it law that Service User and carers groups be part of MDT’s.
- HSE to provide admin support for carer networks- suggestions that they could send an intern or someone attending a Fás course.

- People often surprised what Service User Panels can contribute – need to be taken more seriously.
- Services are viewed as important if there is demand – increase demand by informing the public of their existence.
- Suicidal patients should not be left alone to wait for long periods in A & E.
- Services themselves must be open to change and view service user groups/consumer panels etc as productive – opportunities to learn.
- Lack of accountability – no checks on how resources were being spent, no consultation with service user groups and nothing was being done about "burn out" in staff of mental health services which leads to complacency.
- Service users were not sustained in their community due to insufficient community services – leads to increase in admission with longer stays and increased likelihood of relapse.
- More services need to provide welcome packs to users to let them know what their rights and obligations were and why certain measures were taken (example given of taking patient's phones without explanation).
- Everyone had their own interpretation of A Vision for Change this formed an agenda that was rarely discussed with service users.
- A Vision for Change focused too much on hospitals with little guidelines for community centers.
- Complaints of ongoing paternalism – No choice in consultant, had to go along with whatever they said.
- Broad consensus on the problems with making a complaint and the need for an independent complaint mechanism and accountability.
- One service user reported fear of making a complaint because of worry of being labeled "manic".
- No clarity on who you can make a complaint to or whether you could trust the staff.
- Too afraid to complain in case of reprisal from staff, lengthening of detention or worries that in the future may need to use the service again.
- Worries over complaints inhibit service users from being completely honest with their consultants.
- One service user suggested that the MHC should send people to Mental Health Services posing as patients and draft a report as it was the only way to gather facts on the ground.
- Service users needed more say and choice in treatments offered to them, e.g. less medication, more talking therapies.
- Communication between support groups needed to improve.
- Old culture of entrenched middle management doing things the old way needed to change.
- Lack of financial support to service users attending mental health service committees.

- Need more services to be offered in community settings.
- Need a greater range of services based on needs of service user.
- Need to keep challenging the power imbalance between clinicians and service users.
- Communication to service users about treatment plans, by staff, needs to improve in some areas.
- Need full multidisciplinary teams to be in all areas and to include a service user and carer representative.
- Consumer panels need to be allowed to participate in management of mental health services.
- Still lack of meaningful activities in some approved centres, making boredom a problem.
- Make it "mandatory" for mental health services to implement A Vision for Change, e.g. Have service user representatives on community mental health teams, management boards etc.
- Facility for service user to have element of choice in their Psychiatrist/service e.g. money follows the patient, patient can vote with their feet.
- More focus on inspection of mental health services other than Approved Centres. Dr Devitt clarified that the Inspectorate also inspected non approved centers and pointed out that our focus on ACs was because it was here that the disparity in power between service user and provider was at its worst.

Definition of Recovery

- Need true respect for the service user's viewpoint.
- "This is what we, the people using your service, want".

Effects of reduced resources

- Disappearance of financial support to groups.
- Disappearance of promised posts?
- Lack of accountability at management level as to where the money is being spent.

Summary

It should be noted that while common themes emerged at this national overview meeting, particularly in relation to changes that were needed, some parts of the country were not represented on the day. This may have resulted in a somewhat incomplete picture of the views of service users, carers, family representatives, advocacy groups and consumer panels.

Positive Themes

- Attitudes were at last slowly changing towards a partnership approach.
- Individual Care Planning had improved in many areas.
- Service user involvement on Community Mental Health Teams (in some areas) was making a real difference.
- The Inspectorate's report can be very helpful in encouraging improvements in services e.g. Individual Care Plans.
- There was an increase in consumer panels and advocacy groups around the country.
- New Community Mental Health Teams were making a real difference (in some areas).

Negative Themes

- Lack of consistency in quality of mental health services around the country. This was in relation to involvement of service user voice, availability of community based services, range of choice of treatment options in hospitals, overreliance on medication, "every area seems to have its own vision of "Vision for Change".
- Lack of resources means promised new services and multidisciplinary teams have not been put in place, also service users groups were suffering from lack of financial support.
- Communication between different support groups needed to improve.
- Boredom and lack of meaningful activity still was an issue in many centres.
- Service users still afraid to make a complaint in some areas, particularly if they were involuntarily detained.
- Complaints procedure not seen as independent enough.
- A culture of disrespect still existed among some clinical staff.

- Some mental health services still do not understand that Recovery for service users means…" this is what we, the service users, want".
- More services needed to provide welcome packs/information to service users to.
- Poor links with other services such as housing and employment.

Conclusions of this group

1. Service users need to have a more active role in the planning and delivery of mental health service, through participation on consumer panels, management and clinical governance teams.
2. Service user groups would benefit from closer collaboration.
3. Need for an independent complaints procedure in mental health services.
4. Staff in mental health services should always treat service users with dignity and respect.
5. Need for more choice of treatments both in community and in-patient settings.
6. Need more community based services.
7. Need to have multidisciplinary teams fully staffed as truly multidisciplinary.