

# **2010 National overview of service user, family/carer and advocacy involvement in mental health services**

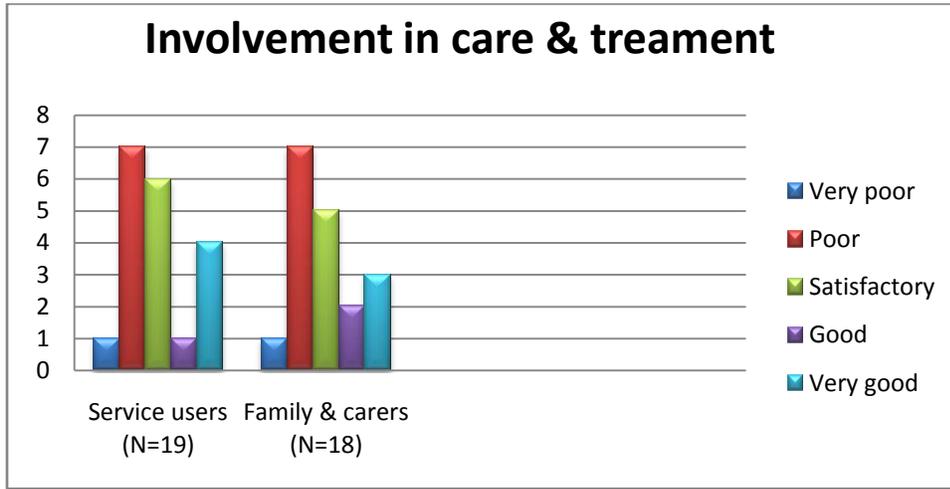
## **Background**

Last year the Inspectorate reported on service user, carer and advocacy involvement by asking services to comment on their performance on a number of parameters based on the Quality Framework document published by the Mental Health Commission (2007). This year, the Inspectorate decided to report on this area by gathering information about the perspectives of service user representatives, carer representatives and advocacy representatives in relation to their involvement at different levels within the mental health services from care and treatment, to management, planning, development and evaluation of mental health services. Their views were gathered through a survey conducted by the Inspectorate to which there were 31 respondents and via a national overview meeting where representatives of service users, carers and advocate organisations were invited to attend. Unfortunately due to adverse weather conditions many representatives were unable to attend on the day of the meeting. In total there were 12 representatives present and they formed three groups representing service users, family and carers, and national organisations with an advocacy role in relation to mental health, for example, the Irish Advocacy Network (IAN), National Service Users Executive (NSUE) and Mental Health Ireland. Of note, it was difficult to obtain information about service user and carer/family representative groups operating within the mental health services.

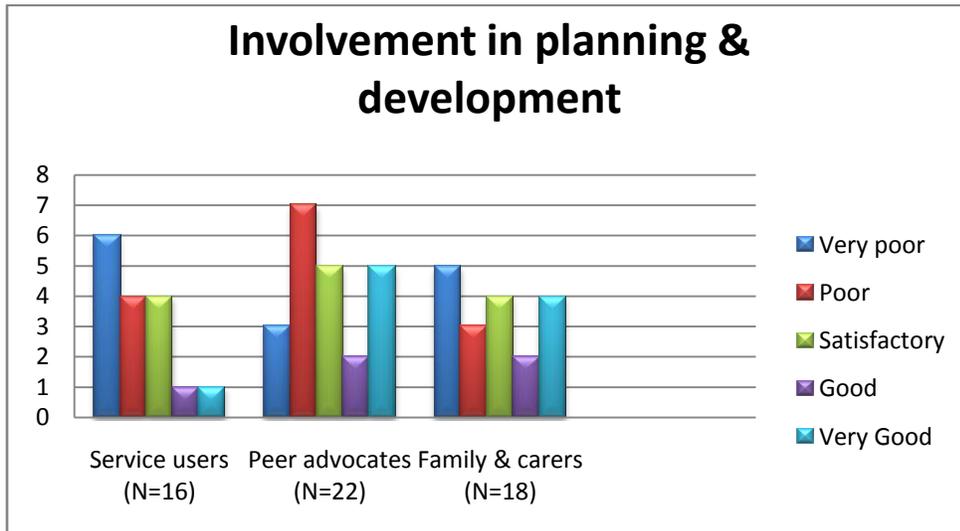
## **Summary of survey**

Thirty one questionnaires were returned from service user representatives, family/carer representatives and advocates from a range of Health Service Executive (HSE) and voluntary agencies. A summary of the responses for each question is presented in graph form below and indicates the number of respondents who rated the service as very poor, poor, satisfactory, good or very good.

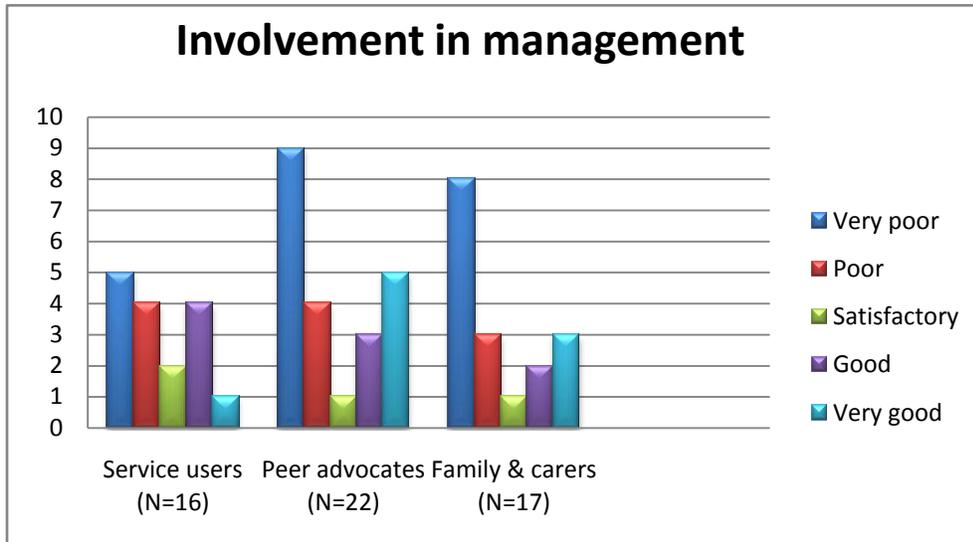
1. Rating of mental health services on how it involved service users and family/carers in care and treatment planning.



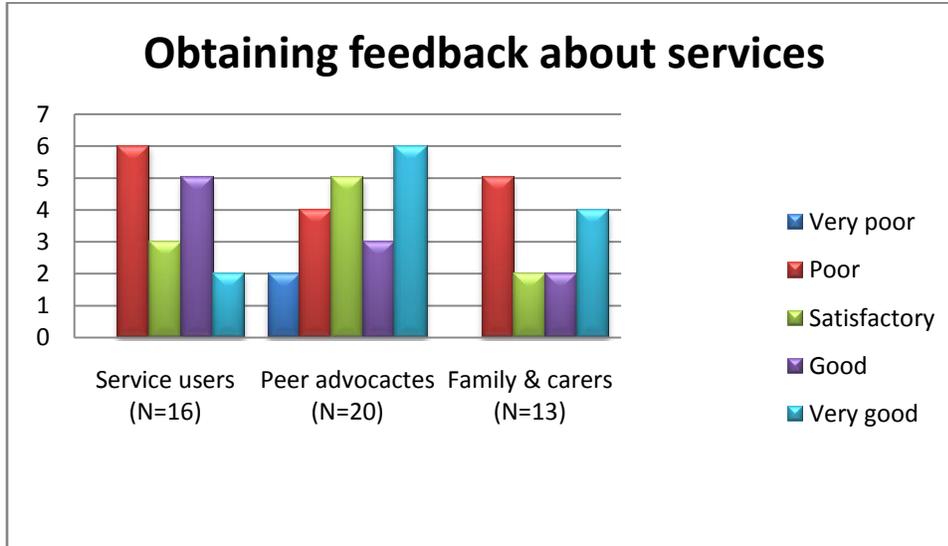
2. Rating of mental health services on how it involved service user representatives, peer advocates and family/carer representatives in the planning and development of services.



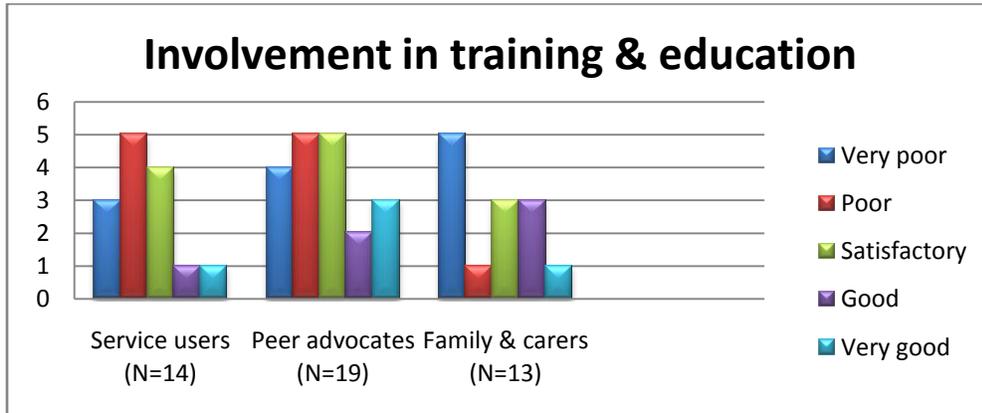
3. Rating of mental health services on how it involved service user representatives, peer advocates and family/carer representatives in the management of services.



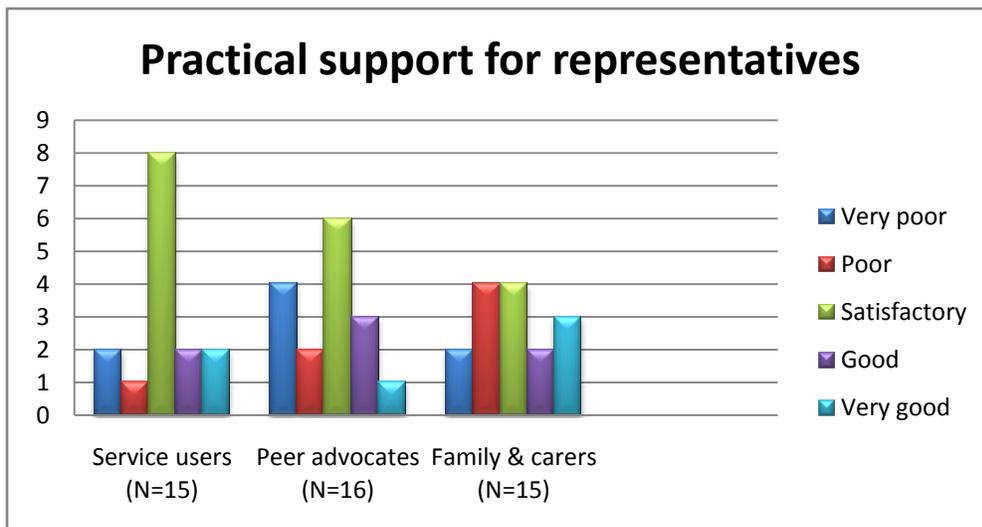
4. Rating of mental health services on how it obtains feedback from service users, peer advocates and family/carers about the services it provides.



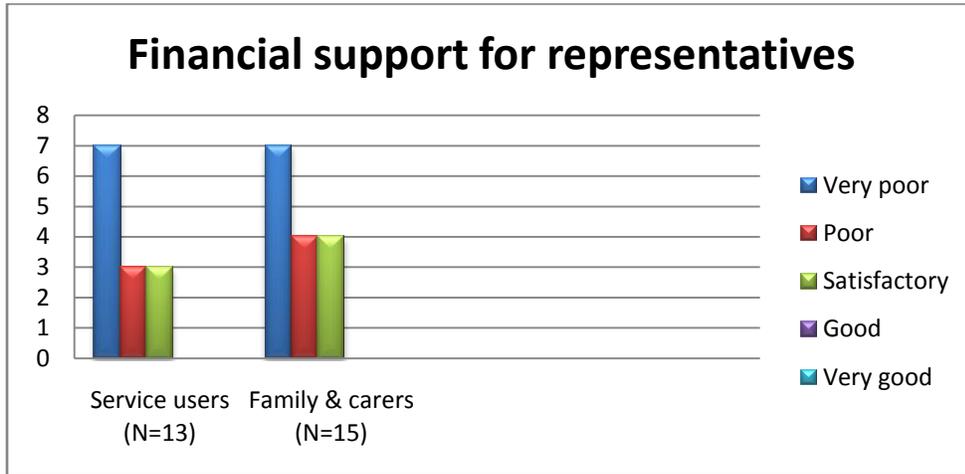
5. Rating of mental health services on how service users, peer advocates and family/carers were involved in the education and training of staff.



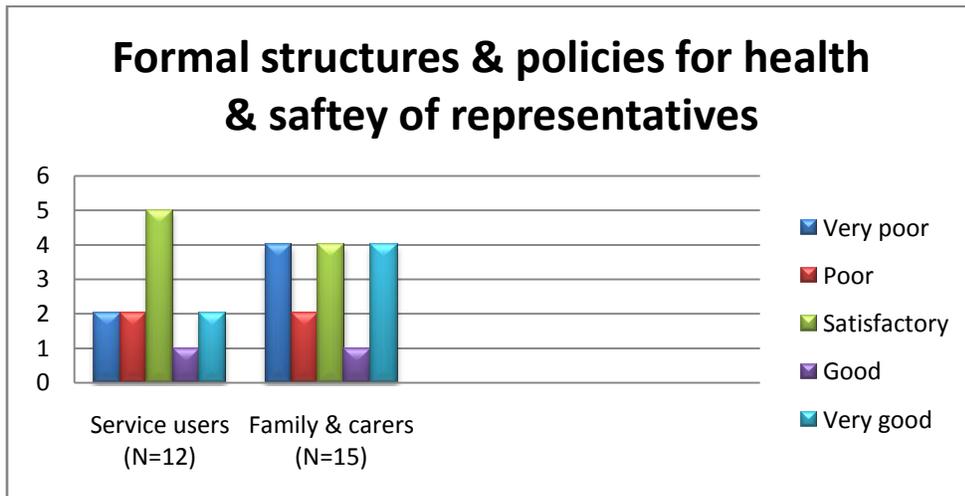
6. Rating of mental health services on the level of practical support it provided for service user representatives and family/carer representatives.



7. Rating of mental health services on the level of financial support provided to service user representatives and family/carer representatives to carry out their work.



8. Rating of mental health services on formal structures and policies in place for the health and safety of service user representatives, family and carers representatives and peer advocates.



## Summary of National overview meeting

At the national overview meeting, representatives of service user groups, family/carers groups and national groups that advocate for mental health were asked to report on:

- 1) Three highlights about service user/carer involvement in relation to care and treatment, and planning and management of services.
- 2) Three low points or barriers about service user/carer involvement in relation to care and treatment, and planning and management of services.
- 3) Three cost neutral or practical recommendations that services could implement that would enhance service user and carer involvement in care and treatment and planning and management of services.

## Highlights about service user/carer involvement in relation to care and treatment and planning and management of services.

*Service user representatives:*

- The positive impact of individual care plans where these had been implemented properly, with a written plan and active service user involvement.
- Having a felt sense of being cared for.
- Receiving information and being helped to be informed about their illness.
- Staff instilling a sense of hope and reassurance about recovery as a possibility.

*Carer representatives:*

- Recognition of carers as having needs and carers putting their needs forward.
- Good conditions in some services.
- Creating a positive approach to mental health.
- Active involvement of carers in individual care plans.

*Advocacy representatives:*

- Consumer panels and residents associations.
- Complaints procedures that were taken seriously and work properly.
- Individual care plans that involved service users and carers.
- Meetings that were sensitive to service user and carer needs and sensitivities.

## Low points or barriers about service user/carer involvement in relation to care and treatment and planning and management of services.

*Service user representatives:*

- Disrespect in action and in words, for example, staff being rude and patronising, no equality in how staff and service users were treated.
- Non consultant hospital doctors (NCHD) rotating every six months and having to tell one's story over and over to new doctors. If information was read from file many of the questions could be answered.

- Care workers not showing respect and not adequately trained, coupled with a fear of complaining about them in case of retaliation.

*Carer representatives*

- Lack of activities for in-patients at weekends.
- Not enough multidisciplinary teams.
- Resistance of professionals to change.
- More follow-up and ongoing care.
- Lack of outpatient services apart from Emergency Departments. Emergency Department visits often entail long waiting times for people who can be very distressed and confused.
- No sympathetic way of transporting ill person to hospital other than by involving Gardaí.
- Mental health care professionals' poor attitudes to carers.

*Advocacy representatives:*

- Fear and intimidation prevented complaints.
- Choice of consultant psychiatrist was limited and exercising this choice was made difficult by services and staff. Service users who want to change consultant should be taken seriously.
- Uncertainty about inspection of private facilities, for example, nursing homes.
- Lack of sensitivity of impact of changes on service users and carers for example, amalgamation of services does not take into account fear and anxiety of those using the services about having to start all over again with new staff and in new places.

**Three cost neutral or practical recommendations that services could implement that would enhance service user and carer involvement in care and treatment and planning and management of services.**

*Service user representatives:*

- A change in attitude in how people are treated. Staff need training in interpersonal skills.
- Consistency of service user participation across services and clear definitions of what service mean by service user involvement.
- Making sure staff are more accountable and responsible for what they do, for example, through performance management.

*Carer representatives:*

- Quality of initial staff training and ongoing training in interpersonal skills needs to be better.
- Staff should be redeployed to community services rather than in-patient services.
- More provision for step down facilities.
- More support for families and carers in the event of a crisis.

*Advocacy representatives:*

- Booklets for service users of in-patient and outpatient services that outlines their rights and entitlements, including complaints.

- More facilitation of community based services and better interaction with other agencies with a key worker coordinating communication.
- Psychiatrists to provide explanation of diagnosis and of treatment, and to discuss a choice of treatments.
- More use of individual care plans.

### **During the course of the meeting other issues arose:**

- No transparency in Health Services Executive related to funding of services.
- Funding should follow the service user and the service user should have a choice of which service to attend. Services should be linked to benchmarking.
- The role of the Mental Health Commission and professional regulatory bodies is very important in determining standards and setting out what is, and what is not, acceptable. Service user, carer and voluntary bodies can have concerns about possible backlash.
- Professional regulatory bodies and managers should be more involved in taking firm action with professionals who are not working in line with *A Vision for Change*.
- Services need to avoid paying lip service to service user and family/carer involvement in all aspect and levels of the mental health service.
- Often staff want to have patients whereas family want to have relations who are living a life.
- Patients have been discharged from services for non-attendance and have not been informed of their discharge.
- There was inconsistency across services in terms of processes and structures and often conflict between neighbouring services fighting for limited resources reflecting self interest rather than the interests of the people being cared for.

### **Recommendations**

1. At a minimum, every service user should be involved in developing their individual care plan and be offered a written copy of it.
2. Each service should introduce one new initiative to enhance service user, family/carer and advocacy involvement in 2011.