Health and Social Care Board
Public Health Agency

USERS AND CARERS AS STAKEHOLDERS IN THE DELIVERY OF ADULT MENTAL HEALTH SERVICES; PROPOSALS FOR REGIONAL SERVICE IMPROVEMENT

Introduction

Since the publication in England of the National Service Framework for Mental Health in 1999 and the subsequent NHS plan (2000), there has been a core policy requirement that services in general and mental health services in particular should be tailored as far as possible to the needs, preferences and wishes of service users and carers. This requirement is aimed at producing a patient/client/carer led and person centred service that contributes to achieving a positive experience of using services .

In modern adult mental health care, it is a mark of excellence to achieve proven mutual respect, openness and partnership between those who plan and deliver services and those who use these services or care for someone who does. This is best demonstrated through user and carer involvement in the design and delivery of mental health services.

Service users and carers are not all the same and have a number of different and legitimate views of their role. Some may see themselves as ‘lobbyists’ operating outside mental health services and offering a constructive criticism of how to improve services. Others may regard themselves as ‘consumers’ with consequent and legitimate rights but without any real say in how to make services better.

However, both these roles also have potentially negative connotations in that there is no sense of being formally ‘involved’. There is the possibility that users and carers adopting these roles will continue to be excluded with the possibility of negative ‘tensions’. Neither role necessarily promotes the concept of partnership.

A different view of the role of people who use services and those who care for them is to view them as stakeholders who have a vested interest not only in being consulted in an ongoing way as partners but also in shaping and improving the quality of the care they receive.

Service user and carer participation in the planning, design, commissioning, delivery, monitoring and evaluation of services is no longer an aspiration for HPSS staff responsible for adult mental health services. It is now a necessary aspect of a modern and ‘fit for purpose’ adult mental health service. The concept is not new and in various locations, staff, users and carers have been working in partnership at different levels. What is now required is that this becomes standardised practice across the region.

The Health and Social Care Sector in Northern Ireland is now required to promote personal and public involvement in its functions and, under Section 19, to *'promote information about the health and social care for which they are responsible and to seek views from the recipients of health and social care either directly or through representative bodies'.* This requirement has now been given further impetus with the endorsement of the Bamford Action plan by the Northern Ireland Executive.

Who are service users and carers?

A 'service user' may be defined as a person who has had direct personal experience of receiving mental health care from services, whether from publicly funded or private services. For those who have contact with statutory secondary care services, this means the user will typically have had contact with a GP, psychiatrist, psychologist, mental health nurse, mental health social worker or occupational therapist. GPs are independent contractors within the NHS and as such have a vital role in the delivery and gatekeeping of mental health care system . As a profession, this group of practitioners are responsible themselves for listening and responding to the voice of users and carers.

Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member.

Building the partnership

There are a number of levels at which service users and carers could develop an initial level of participation, influence and partnership;

- Policy making
- Service planning and design
- Commissioning of services at regional and local level
- Service delivery at organisational and individual level
- Participating in the development of and having a copy of a written care plan
- Production or assistance with the production of relevant documentation in plain and jargon free language
- Staff recruitment
- Undertaking paid caring roles as professionals or as support staff
- Staff training
- Governance processes

It is however recognised that a meaningful and equitable partnership will not be defined by the Board in a prescriptive way but rather will develop its own remit, principles, functions and methods of engagement.

Service users and carers (as a group of partners) will wish…

- to be treated with dignity and respect

- to have good information (written in plain English or other language or in an appropriate format) about the services they are using and relying upon
- to understand the structures and systems that are used for planning and delivering care
- to be involved (in so far as possible on the basis of equality) with responsible professionals and managers involved in planning and delivering care
- to be involved (in so far as possible on the basis of equality) with those responsible for commissioning and procuring services at regional and local level
- to be involved in treatment, care and support decisions about themselves
- to understand the reasons behind any decision to exclude carers from decision making (for example, through the choice of the user)
- to be able to ask challenging questions and offer useful opinions about their treatment, care and support
- to have access to advocacy services at their discretion
- to have choice about whom they receive care from
- to be able to initiate a formal review of their care plan
- to request and receive an assessment of their needs as carers and to have confidence that this information is utilised for planning and service delivery purposes

These functions are predicated on a number of underlying assumptions (which may or may not accurately reflect what actually happens in practice);

- That good information is provided to users and carers about service delivery and planning systems and processes
- That there is documented and transparent clarity about roles and responsibilities in the planning and delivery of services
- That there is documented and transparent clarity about structures and systems that support the planning and delivery of services

With the advent of new commissioning structures involving both the Health and Social Care Board and Public Health Agency operating across the region, it is important that the core elements of user and carer involvement and participation as partners must be consistent in all locations in order to achieve equality and equity. This can most easily be achieved by creating a minimum of two places on the regional commissioning team for user and carer representatives to participate in the commissioning of mental health services.

There is also now a case for a single regional network representing users and carers that will act as a strategic link to promote service user and carer’s involvement and to ensure regional consistency. There a statutory aspect to this function embodied within the recently created Patient and Client Council (PCC). A new regional mental health user and carer forum could operate under the auspices of the PCC, derive some of its membership from there and could take advantage of the PCC’s proposed email database. The exact nature of the relationship between the forum and the PCC requires further exploration and articulation.

In order to make this service improvement, service user and carer groups need…

- to be funded
- to have a place to meet
- to elect their management committees and representatives
- to be more representative of minority group interests (in line with the Northern Ireland Act, 1998)
- to have paid workers acting on their behalf

Service user and carer groups should…

- Provide self-help and social support
- Participate in formal commissioning and service delivery management structures
- Make themselves available for consultation
- Help with the education and training of staff
- Promote creative activities
- Campaign proactively on behalf of their members
- Advocate on behalf of other service users and carers

Service user monitoring projects should be based on the principles of User Focused Monitoring (from the Sainsbury Centre, 2007), that is;

- Projects should be led and controlled by service users

- There should be a clear focus on service development and improvement in services that are most frequently used, particularly by marginalised groups
- There should be an active commitment to involve service users who have had direct experience of using the services being monitored
- There should be an aim to disseminate findings widely
- There should be a commitment to addressing quality issues
- There should be project independence
- The group should follow good standards of research methodology
- The group and their coordinator should receive supervision and support
- Training should be provided to the project team
- Commissioners and providers should commit to implementing the recommendations of any report

A proposed way forward

The Health and Social Care Board and the Public Health Agency will further promote the involvement of mental health service users and carers at all levels of service planning and delivery. This is so that users of mental health services and their carers have a more meaningful and positive influence on the planning and delivery of these services. The Board and the Agency also wish to ensure that minimum standards in relation to this partnership are delivered throughout Northern Ireland as part of the process of reform and modernisation.

To this end, the Board and the Agency will implement the following core proposals;

- The development of a regional user and carer forum with autonomy to generate its own focus but initially tasked with the process of ensuring the adoption of the following minimum standards throughout the service; (membership of the forum will be by nomination facilitated by the Patient Client Council and from local Trust fora and will be for a fixed term, with the option to renew)

    - The development and delivery of capacity building training for Users and Carers representatives within each Trust. This will be delivered independent of the Board and, if possible will be delivered by users and carers themselves and based on their own needs assessment.

    - User and carer participation in HSCB and PHA commissioning and Trust operational management structures

    - Participation in the recruitment of relevant staff grades, initially for all appointments at Band 8A or above within mental health services where the member of staff to be appointed will have contact with the general public and/or mental health service users and carers

- The establishment within each Trust (where such is not the case) of a user and carer forum formally recognised by the Trust as representing the views of users and/or carers – members of such fora will need to be actively and demonstrably involved in other organisations and user/carer ‘communities’ more widely as a function of their membership of such fora. If there is a need to identify a separate group locally to reflect the separate needs of carers, this will be done.

- The participation of this forum in relevant training initiatives

- Other issues as identified by service users and carers, in particular the exploration of how Trust/Board/PHA appointments can be made accessible to service users and carers as potential applicants

- The development of common processes and systems for the payment of travel and other reasonable expenses to enable service user and carer participation in these activities AND the development of proposals for the payment of users and carers when they participate in service reviews, in-depth monitoring exercises or other quality assurance processes alongside professionals engaged in the same process. (The HSCB in partnership with PHA and PCC will aim to produce a paper by 31 October 2010 dealing with this topic. It is anticipated that it will be substantively based on the Southern Health and Social Care Trust policy of November 2009)

Board members are asked to approve the implementation of these recommendations.