

Health and Social Services Committee

HSS(2)-13-04(p.3)

Date: Wednesday 3 November 2004

Venue: Committee Room 3, National Assembly for Wales

Title: Mind Cymru Evidence, Policy Review NSF Standard 2

Introduction

The evidence given in this paper is based on evidence given in response to a Mind Cymru survey of service users, carers and groups.

A questionnaire was issued to all Mind's networks and focussed workshop sessions run in 2 local Mind Associations at meetings open to all Mind network members. Consultation was also undertaken at one network's residential meeting.

Forty written responses and the oral evidence given by an additional forty-four people have been analysed and used to inform Mind Cymru's response to this Policy Review.

Care Plans

Some respondents had ideas of what care plans are, or should be. The overwhelming majority did not have a care plan. Those that did had little or no input into drawing up their care plan (with the exception of four examples of good practice, see section 5).

The content of care plans was spartan and biased heavily and in most cases solely towards medication.

"...the result of this (CP) was that they doubled my meds. immediately.."

We are very concerned that the evidence suggests there is still a lack of clarity and knowledge amongst all those who are/should be involved in care planning, including mental health professionals. This needs to be addressed urgently, through relevant education and training.

"These 'care plans' aren't really care plans; they're statements of intent."

1. Full and Genuine Participation

It is Mind Cymru's view and the view of our members that full participation means input from users, carers (and other user involved supporters and services as appropriate) at every part of the process, from planning, through to delivery and monitoring and review of the process. This holds for individual care planning and service planning and delivery.

Genuine participation means holding service users and carers in the same regard as other professionals involved in service planning and delivery.

Genuine participation allows users and carers to challenge aspects of care planning and delivery, with those challenges acknowledged and used to inform the process.

2. Barriers

The first barrier is getting the relevant people to meet at the required time. Evidence was given that often meetings are not attended by professionals and/or there are significant delays in waiting for appointments.

The shortage of psychiatrists and the high turnover of staff are also barriers. High staff turnover leads to a lack of mutual understanding and can lead to a lack of trust. Relationships have to be re-established and staff often do not have the time to spend with users familiarising themselves sufficiently with their individual needs.

Many service users cited lack of understanding and involvement of them by staff. Their views are not considered with the same worth as professionals, despite being the expert in their own case, "Users should be fully involved at all stages of care planning as they are the ones on the receiving end of it".

A significant barrier is lack of impact on service planning and delivery of the views of service users (see 6).

Other barriers are lack of resources and services in some parts of Wales.

Users in rural areas gave evidence of lack of public transport as a barrier to involvement.

Dual diagnosis can also be a barrier as people's perceptions of the service user change. "I was asked 'why are you here? This is for people with mental health problems, not alcoholics'."

Barriers to carer involvement include, work, family and other time pressures. Childcare and/or dependent care is expensive and cannot be assumed as possible by professionals.

Service users need to be asked if they want their carer to be involved. It should not be assumed that they

do/do not.

3. Overcoming Barriers

In order to overcome barriers there needs to be a review of care planning strategy and training in roles and responsibilities.

The lack of knowledge referred to above needs to be addressed through training and ongoing evaluation and development.

Service users and carers must be involved in their own care plans and in planning service delivery. However they first need to have full understanding of what a care plan should contain. More importantly they need to be involved in coming to the decision of what a care plan should contain. The respondents all want to have a real role in shaping their care now and in the future. Most wanted carers to be given the opportunity and the means to be involved. This could be done through timing of planning and review meetings taking account of carers' commitments.

4. Roles

All sectors as detailed below have a role and duty to work productively together and ensure lines of communication between them are open and effective. There is a need for clarity in processes involved; e.g. is this consultation or decision-making?

i. LHB

As the commissioning body they are responsible for service provision. They should deal with policy issues. The LHB should look at provision and the identified gaps in provision and consider these in their service planning. An example given was if a service user wanted a counselling or holistic approach, the LHB could/should consider funding.

They should identify areas of good practice and ensure this is adopted as the norm. They should ensure that the Care Planning Approach is implemented and monitored.

Awareness raising programmes should be implemented by the LHB.

ii. NHS Trust

The trust should work in partnership with the LHB to oversee and maintain quality. The trust should not get too involved with policy but focus on supply of resources to meet demands. It is strongly believed that the trust should ensure effective and open lines of communication between all other partners in CPA and mental health service delivery.

The trust should liaise fully with the voluntary sector and service user and carer groups and ensure user/carer representation on planning groups is effective and respected.

There is a role for the trust in staff retention and recruitment. Many respondents believe it is the role of the trust to motivate staff. The trust should provide leadership and accountability.

iii. Primary Care Team

The primary care team is very important. "As the first point of contact for many users the primary care team should be actively involved in care planning."

Involvement of the PC Team would lead to less fragmentation and a move towards "..seamless service.."

They have a role in breaking down barriers, as often the first barrier is at this level, trying to get an appointment. Many service users regularly experience delay and difficulty in seeing their GP. Seeing the same GP is also a problem leading to a lack of continuity of care. The role of dentists, nurses, as well as GPs needs to be joined up.

iv. Voluntary Sector

The role of the voluntary sector is to work with the statutory sector, to challenge and to highlight areas of good practice. To empower service users and support their development. Issues of confidentiality can arise if there is direct involvement in individual care plans so they need to focus on the strategic and operational aspects of service policy, planning and delivery, including monitoring and review.

Service users feel strongly that voluntary sector services should not be seen as a way for statutory bodies to divert resources away from mental health services thereby not meeting their obligations, but that the voluntary sector should provide alternatives.

The voluntary sector is also able to put forward the views of service users and carers through consultation.

The role of advocates is considered in a different light, as they should be involved in individual cases, supporting users and/or carers.

v. Local Authority

The local authority should have equal participation and should work in partnership with the other sectors on the mental health agenda.

They have particular roles with regard education and social services and quality assurance.

The L.A. should look at good practice and also plan education and training in mental health issues, starting at secondary school level.

The role of social workers is crucial and the consultation group raised strong concerns that the new mental health bill proposes replacing the Approved Social Worker with the approved mental health worker. Under the current Mental Health Act the ASW is the only non-NHS based mental health professional in the team, giving a degree of independent support for service users. Concerns are voiced that this independent role of the L.A. must be retained. This concern formed one element of the oral evidence given by Mind Cymru to the H & S C committee on the MHB on 14th October 2004.

vi. Service Users

Service users must be included in all aspects of their own care planning and delivery. They have the right to express an opinion if care plans are not favourable and should shape their care plan package. "... they should be driving force – but would need to know exactly what things could go on it."

Service users should also be integral to service planning and delivery. They should help shape CPA.

Service users need to be self-accountable and challenge practices leading to improvements.

Service users also have a role in peer support.

It is cited by some respondents that service users have a role in breaking down barriers, barriers are not always put up by one sector of the partnership.

Service users are the experts and need to act accordingly. They also should be treated accordingly in terms of status and remuneration. A concern is that currently service user representation is ad hoc (please see 6).

vii. Carers

Firstly it needs to be recognised that a lot of people are service users and carers. This dual role is significant and needs to be taken into account.

The role of carer as listener and empathiser is well known but they lack a place in current care planning arrangements in the experience of most respondents. Carers are often "the invisible support sector".

Carers should have a substantial role in individual care planning in the majority of cases, as they know the service user well. However the permission of the service user is required. "If the carer plays a significant part in the success of a service users care – they should be involved at every review."

There is a potential and sometimes actual conflict of interest between service users and carers and all parties must be mindful of this.

There is also an issue where professionals are carers for service users. Also paid carers have a different role and it may or may not be appropriate to involve them in care planning. The view of the service user is paramount here.

5. Good Practice

Examples of good practice in care planning are few and far between. The majority of respondents could not give any evidence of good practice. Where examples do exist it is in pockets in different areas of Wales, but they share common themes. Four respondents gave individual examples of good practice in Newport, Ceredigion, Monmouth and Powys.

In all four cases they are involved in care planning and shaping their own plan. They are consulted and contribute to the content of their care plan. In all cases they cite the joint working of a range of professional and themselves as being pivotal to good practice.

In one case the service user writes the plan on a regular basis in consultation with the CPN.

In another case the carer is always given the opportunity to attend. However work commitments prevent attendance.

A carefully chosen venue is used on one example where the service user does not feel threatened and is therefore more able to be fully involved.

Good practice in England needs to be taken into account. Evidence was shared from Beacon Projects.

Other examples of good practice in the relationship between the service user and individual GPs, CPNs and/or psychiatrists have been shared.

The view of respondents is clear. These examples should not be seen as 'good practice' but actual practice in all aspects of CPA throughout Wales.

6. Stigma

There is still much evidence to show stigma and discrimination do exist. The wider issues of stigmatisation are documented elsewhere, not least in evidence given in the Implementation and Advisory Group Anti Discrimination Working Group, led by Dr. Zoë Thomas. In this consultation we have focussed on stigma and discrimination in user and carer participation.

There is much evidence of stigma and discrimination. Service users and carers are not involved in care planning.

The consistent thread throughout the examples is of a lack of regard for service users and carers views. Many examples of care packages, whether written or verbal, being simply presented to the service user are given. This practice is the norm for the survey population.

"Nurse arrived with a care plan done for the person who was service user without having even met him."

"On the acute inpatient ward you actually receive a care plan. You are told how things will be and not given any option to contribute to it."

"Staff attitudes are most difficult to change."

"If I act normal people leave me alone. If people can see that I'm unwell they take advantage of me!"

"My consultant informed me this year (2004) that, 'the illness does not go away'... They should know better than to use terms such as this."

"Once a service user accepts a service/support they are labelled and treated according to this label".

Evidence of stigma and discrimination by professionals towards service users at planning groups, which have service user members, was cited. Examples given from different parts of Wales included being belittled by a professional who had had some minor professional involvement in the service user's care some years before, and the feeling of marginalisation from professionals on the group. "I have been treated as a 'token user' on some user participation councils..."

A further concern is the potential for service user representative to be less than representative of service user views if service users or service user groups are not involved in selection. Evidence was given of this practice.

Tackling Stigma

In terms of care planning, stigma and discrimination would be tackled if service users and carers were actively involved. If CPA is fully adopted and safeguards of training, monitoring and review are put into place, service users and carers will have equal status with professional and service providers.

In the wider context education and training are needed to breakdown barriers. Service users cite lack of understanding and fear as major contributors to stigmatisation and discrimination. This needs to be urgently addressed in a planned and joined up manner. This is a joint responsibility of all sectors and must include service users and carers in planning, delivery and evaluation.

Other Concerns

Service users raised as a particular issue the use of ECT under the proposed mental health bill. Service users are extremely concerned about the use of ECT and the potential side effects of this treatment. The safeguards are not strong enough and Mind opposes the new power under the MHB.

Conclusion

The evidence from service users and carers is very strong. There is still a lack of involvement and stigma still exists.

The issues raised in this paper need to be addressed in order for service users and carers to be involved in CPA; and for the National Assembly for Wales to meet it's obligations under the Better Wales Strategy, the National Service Framework Standard 2 and the recommendations of the Wanless Report.

I confirm that we will give oral evidence as requested on 3rd November 2004.

Mind Cymru Networks Invited to Respond

Mind Link, Mind and Body, Mindout Cymru, Diverse Minds. LMA Directors and Co-ordinators and Cyngor members were also included