

User Involvement in Mental Health Services: A Study in Grampian

This study aimed to explore user involvement activities within mental health services in the locality from the perspectives of those who take part. Its focus was on how user involvement can influence the help available to women and men experiencing mental distress. This briefing paper presents an overview of findings and is intended to generate discussion and comment.

Key findings

- Service users reported deciding to take part in user involvement initiatives in order to help both themselves and others. However they saw the level of their involvement and influence within statutory mental health services in the region to be limited at present.
- A number of benefits and barriers relating to user involvement were identified:
 - **Speaking.** User groups and initiatives can give service users a voice and forum for discussion. However there remains a great deal of silence among service users, many of whom still find it difficult to speak out.
 - **Taking part.** The importance attached to users' views and feelings of discomfort about taking part in meetings were key issues for service users.
 - **Understanding.** Shared understanding and a sense of solidarity were seen as important benefits to the individual of user involvement. However the difference in perspectives between users and providers of services also presents a challenge for user involvement.

- **Giving and taking power.** Service users thought that mental health professionals need to 'give up' some of their power in order for user involvement to work. However they also emphasized the difference between involvement and empowerment (defined as being helped to help yourself and as linked to understandings of mental distress).
- **Seeing differences and inequalities.** It was felt that differences and inequalities among users and providers were often overlooked in the context of user involvement, which tended to see the user voice as a single and unified entity.
- User involvement was generally seen as a positive development in relation to mental health services, although some felt that collective advocacy and political organising were better ways to achieve influence.
- Recommendations of the study include the need for those developing user involvement initiatives to consider both 'cultures' and mechanisms of involvement; to take into account difference and inequality both between and among users and providers of services; to ensure service users feel listened to and understood; to provide clear explanations about the aims and limits of user involvement; and to recognise different understandings of mental and emotional distress.

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Background

User involvement is a recent key development within mental health services in Scotland. It refers to the active participation of service users, both in decision-making about individual treatment and care, and in influencing the development of services more generally. Different levels of user involvement can range from simple information-giving/explanation, through consultation to shared decision-making with professionals and user control. Campaigning (or collective advocacy) may also be considered a form of user involvement. Forums and structures that enable user involvement include:

- Local or national user groups/networks.
- User-led charities, social firms and services or self-help groups.
- Patients' councils within hospitals.
- Local reference groups for service users and providers.
- Users participating on national policy-making bodies.
- Local or national user consultation exercises.

Although a policy requirement, the difficulties of achieving 'shared' decision-making between users and providers within mental health services in Scotland have been noted (Loudon and Samuel, 1999). In addition, concern over the outcomes from various forms of user consultation has been expressed (Hardie, 2003). However, the development of user involvement has varied across localities in Scotland.

The study

This doctoral study was conducted over three years (Dec 2001-Nov 2004) and funded by the Medical Research Council. It aimed to explore user involvement activities within mental health services in the locality from the perspectives of those who take part. Its focus was on how user involvement can influence the help available to women and men experiencing mental distress.

The study used a variety of methods to explore user involvement activities within mental health services in the

Grampian region of Scotland, focusing on Aberdeen City. These included 31 interviews with members of three different groups: Aberdeen Mental Health User Network, Aberdeen Mental Health Reference Group and Moray Mental Health in Elgin. 25 of these interviews were with service users, 5 with mental health service providers or practitioners, and 1 was with an MSP. Other methods of gathering data included an initial mapping exercise, attendance at group meetings and analysis of national and local policy documents (*Framework for Mental Health Services in Scotland* [1997-2004] and '*New Horizons – A Joint Endeavour*': *A Framework for Mental Health Services in Grampian* [1998-2004]).

Findings

Reasons for getting involved

Service users described deciding to take part in user involvement initiatives in order to help themselves and help improve mental health services for others. Service providers said they engage with user involvement as a requirement of their jobs and in order to gain useful insights from service users about the services for which they are responsible.

Levels of involvement & influence

Despite the development of a number of ways for service users to become involved in developing statutory sector mental health services in the region, those who have taken part as service users reported that this involvement remains very "tokenistic" at present. A number of users stated that they felt "tolerated" rather than welcomed at service planning meetings and that there was a general "reluctance" towards service user involvement. In terms of the levels of influence, many service users felt that there was little (if any) available to them. Many also described not feeling involved in decisions about their own treatment and care, particularly in relation to experiences whilst in hospital. In general, it was conceded that when it comes to user involvement, "we've got a long way to go".

User Involvement: benefits & barriers

SPEAKING

The value of groups and initiatives in providing a forum for users to give their views and to have discussion was often mentioned, especially by women service users:

If we didn't have that [user involvement initiative], you wouldn't have a voice at all. You think even if it's just a small thing, at least they are taking the concern. You even think if a little seed's planted... you know.
(Female service user)

The benefits of speaking out were also conveyed:

*I felt good that I said it too, because I was very angry about that. I could get that out, and I know that I might not have done anything, no good perhaps has come of it, but I've **said it** ... I said that in front of everybody. That was good for me. I said, 'Right, take that on board'. (Female service user)*

However it was also evident that there was a great deal of silence among service users, often due to a fear of voicing their true feelings and concerns. The stress of voicing criticisms and fear of repercussions – at the personal level of receiving services or of services being cut – could all contribute to people's silence.

Where users were expressing their views, the importance of "feeling listened to" by service providers was regularly conveyed.

TAKING PART

Service users identified the "credibility" and sense of importance attached to their views as a barrier to them taking a meaningful role in influencing mental health services:

You can just write off service users' views, you know, you can. (Male service user)

The ease with which service users' views could be dismissed was seen as being related to having received a psychiatric diagnosis. This also affected service users' own feelings of personal authority:

You can just be labelled paranoid and that's it. (Male service user)

You sometimes get to the point where you feel you can no longer trust your own judgement. (Female service user)

Hence many service users expressed problems of 'confidence' about taking part in user involvement activities. Here social background and gender were also important. Descriptions of feeling "like a fish out of water" at service planning meetings were not uncommon, particularly among women service users. Such feelings of discomfort could mean that "you go to meetings and you won't say anything":

I just feel little compared to them [service providers], I feel insignificant. I want to be involved and to improve things for people, but I just wonder if it's [worth it]. (Female service user)

This kind of discomfort was seen to arise from the expectation that users would 'fit in' to existing committees and ways of doing things:

They'll allow us to sit on the committees, as long as we play by their rules. (Male service user)

You as a service user go onto that committee and you have to adapt yourself to the committee. The committee doesn't adapt, there's no negotiation, no meeting half way. (Female service user)

For these reasons, some felt that a focus on training and support for service users to facilitate their involvement (rather than, say, focusing on service deliverers to teach them alternative

ways of consulting or communicating) was misplaced.

Striking, too, was that many of the service users interviewed hadn't seen local policy documents that were key to the user involvement activities in which they were participating. Furthermore, such documents were often not perceived to be publicly available to them. At times users also seemed unclear about the 'point' of their involvement or of the groups in which they were participating.

However the value of user groups and other user involvement activities in helping to build self-worth and confidence among those who take part was also discussed. To this end, the importance of "both sides valuing each other" and "treating one another with respect" was expressed.

UNDERSTANDING

The sense of shared understanding among the service users that took part seemed evident and was often conveyed as one of the main values of user groups and networks - providing social support and a feeling of solidarity:

I think it's good that people who are like-minded come together ... You feel that people are, feel the same. (Female service user)

However a difference in perspectives between service users and providers was also evident. Expectations of user involvement could differ widely between the two parties. The challenges posed by using personal experience to help plan mental health services were also discussed:

They're thinking of the overall picture, but what about the person? I try to put it to them as the other side of the fence as being the user of the services. (Female service user)

If someone brings their personal experience, gets a fair hearing, and then in the discussion around the table does not come out the priority, then with what grace do they accept that decision, or is their personal experience so harrowing that they feel let down by the system again? (Service provider)

Many service users thought mental health professionals often didn't understand their position – including the level of disempowerment that could be felt:

They just don't understand what it's like to be a patient. (Male service user)

Such problems of understanding were seen to lead to other problems, including users feeling "patronised" and having to cope with subtle (but often unintentional) put-downs. Particularly difficult for service users to bear was the situation where contradictory views and criticisms were attributed to their 'illness'. Such treatment evidently contributed to a sense of anger and frustration among many, and to the often-described 'them and us' attitude towards mental health professionals.

Reflecting on these issues of understanding between service users and providers, one service provider suggested that it's important to recognise that you can't be 'inside' someone else's situation, although at times it may be possible to "draw on common experience" to aid understanding. She also stressed the importance of service providers trying to constructively use what may have been bad experiences for some service users to help improve services for the future:

You cannot put the clock back for someone and try and make amends for something that someone did or said to them when they were in hospital or whatever ... but you can ask them what they think can be done differently. (Service provider)

GIVING AND TAKING POWER

Reference to power and empowerment was central to users' accounts. It was perceived that users can both be 'given' and need to 'take' power:

To incorporate users into the system, people have got to step back and give up some of their power. They've got to make a conscious effort to disempower themselves.

*It's still got a long way to go because people still take the stance that doctor knows best so they are basically still very disempowered, don't realise that really **they've** got to take the power back. As soon as they start asking, they get replies.*
(Male service user)

However service users also emphasized the need to be clear about the difference between involvement and empowerment (something which was not achieved in the policy documents examined):

Empowerment is being given the means to the end ... other people maximising your ability to help yourself. And involvement, well that's helping the professionals decide what to do. So they're totally different concepts. (Male service user)

This notion of empowerment – of helping people to help themselves – was generally considered to be central to good mental health services. The links between notions of mental/emotional distress and personal empowerment were also discussed. Some people felt that understandings about mental health issues that emphasized social, cultural or spiritual factors were more empowering than those centring on individual illness:

More and more I'm coming to see depression as a social illness.
(Female service user)

*It is very important **how you see yourself**. ... [You could say] "I'm someone with a mental health disability", then you perhaps escalate even further to other concepts that get more positive [such as] "I'm someone that has non-ordinary states of consciousness **occasionally**".* (Male service user)

SEEING DIFFERENCES AND INEQUALITIES

The language of 'user' involvement was seen by service users to be problematic in leading to one's relationship to the service "tak[ing] centre stage" and the 'person' being overlooked:

You go along as a service user, and even though it's not meant, with the best will in the world people see you as a service user, because you wouldn't be there unless you had a mental illness. So even though they're trying to combat that, in a sense, what they're still seeing first is the mental illness [as opposed to] the person or the woman or the man, or whatever, you know, it seems to take centre stage. (Female service user)

It was also felt that the language tends to "lump people together" – unhelpful as "just because people have got a mental health problem doesn't mean they've necessarily got anything else in common" (service practitioner). Others commented on how this could lead to overlooking important differences between service users, for example on the basis of social class, gender, ethnicity and age:

The trouble with user involvement is that it isn't user involvement at all, it's user involvement for people mostly with a middle class background, who are articulate, reasonably well educated and can put their views across and don't really have all that much difficulty in fitting in on a committee. The rest of them tend to get left out. (Male service user)

The difficulties faced by women and younger people in this regard were also discussed:

Some women might say “oh well I’m just a wifey from Torry, they don’t really want to speak to me”, and it’s important that they’re the kind of people that people are reaching out to and saying “well actually yes, you are exactly the kind of person that we need to talk to because we need to try and talk to as many people as possible”. (Service provider)

The overlooking of issues of difference and inequality among service providers was another area of concern. For example, male dominance on certain key planning committees in the statutory sector was seen as problematic for the involvement of women service users. Some service users also thought this was an issue because women mental health professionals could be more “empathetic” and ready to “compromise” in situations where there was a conflict of views between users and professionals.

User involvement – a good thing?

Despite criticisms most service users saw developments surrounding user involvement as a step forward and felt that it was important to “keep going” with these as “things don’t happen overnight”. The view was often expressed that “it’s better that they do it [ask for users’ views] than they don’t” as otherwise “the professionals would have a free hand to do whatever they wanted”. It was also felt that on many occasions, user involvement policies could provide a ‘lever’ for reform.

However many also expressed disillusionment at the lack of outcomes from their efforts and some felt that collective advocacy and political organising were better ways to achieve influence. User-led charities, social firms and self-help groups were generally seen as valuable.

Recommendations

- **Cultures of involvement.** Attitudes and ‘ways of doing things’ within mental health services continue to act as barriers to user involvement. They often affect service users’ feelings of worthiness and entitlement to become involved. This is something about which service providers (as well as service users) need to be aware when designing user involvement policies and strategies. Many of those interviewed felt that ‘involvement’ has got to start at the individual level of interactions with mental health practitioners before it can work at the strategic planning level:

I don’t think you’ll change things very much until you change the way that people actually come into the system and I think that’s the problem, that we’re still having people who have bad experiences when they go into hospital or they don’t feel listened to by their psychiatrist. So we’re already building up for the people who in five year’s time will say “I don’t feel listened to”. So in a way it’s really about starting from scratch to some extent - and there are people within the system who are converted, who really want to do a good job. (Service provider)

- **Mechanisms of involvement.** A variety of these should be available and users need to feel that they provide both safe and effective ways for them to convey their views. Involving service users from the outset – including in the designing of user involvement policies, forums and group processes where user involvement takes place – is important. For example many interviewees stressed the importance of service users representing an organisation (rather than just ‘themselves’) in order for their participation to be effective and favoured ‘voting’ over consensus working in group situations. Openness, transparency and access to information are also essential. In group forums, a skilled facilitator is key and users need to know whether and how their views are going to be recorded and used.

- **Difference and inequality.** The social backgrounds and characteristics of both users and providers should be taken into account when developing user involvement initiatives. This is because social factors such as age and gender are likely to be crucial to the development of appropriate services for different social groups. Lumping mental health service users together as a single category is not helpful to anyone.

- **Listening to users' views.** Many service users described the value of discussion and the importance of both being given the opportunity to speak and of "being heard". It is therefore important that they feel both listened to and understood when taking part in user involvement activities. It also seems helpful for service providers to acknowledge that although they cannot always understand the feelings of service users, they can constructively listen to and draw on users' experiences in order to improve services for the future. Initiatives that aim to help service providers and practitioners understand the experiences of service users (e.g. joint training between users and providers/practitioners) remain valuable to user involvement.

- **Implementing users' views.** Service users felt it important that they be "part of the decision-making process, and for evidence that that has happened to be readily available". As one service practitioner put it, "a few little acorns here and there would help benefit partnership working and would also reinforce that people's voices are being heard".

However user involvement policies should also be clear about the aims and limits of user involvement (and user representation) and how this differs from user empowerment. Clarity about the degree of influence available, what service users are expected to contribute and the anticipated outcome is essential (Means and Smith, 1994). As many service users are seeking more than

'involvement', alternatives (including autonomous groups/services and other forms of collective advocacy and organising) should also be encouraged.

- **Understandings of mental and emotional distress.** Users' understandings of their mental illness or distress will not always converge with those of mental health professionals. Hence it is important to recognise a range of views here. These are likely to be important to the types of mental health services and initiatives deemed by service users to be most helpful.

References

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This briefing paper is available in audio format on request.

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