

SERVICE USER PARTICIPATION & INVOLVEMENT... WHO REALLY CARES?

Steve Morgan ~ *Practice Based Evidence* (1/1/06)

The following views are those of the author developed through conversations with service users across many parts of the UK during the last 15 years. They are intended to inform the debate about how constructive and empowering service user involvement may be better facilitated by anyone with an interest.

A recent report (Newbigging, 2005) suggests that NIMHE has not achieved all it originally set out to achieve in the area of meaningful involvement of service users. The organization stated its commitment as part of its inauguration 'to put people who use services at the centre of everything we do' (NIMHE, 2002). At least it has been open to scrutiny against this ambitious intention, even if the scrutiny has been of NIMHE by NIMHE. It should be a prerequisite of any organization that purports to manage and develop service user involvement that they be transparently open to scrutiny of how they implement such a sensitive core area of mental health service development. The report does set out recommendations for further positive progression. The question is whether they really go far enough to meet the policy sound-bites from central government about recovery and social inclusion.

WHAT DOES IT ALL MEAN?

For an independent observer with a wealth of anecdotal information from service users experiences, service user involvement in mental health services could easily be seen as an exercise in *encouraging as many people as possible to travel distances at unsuitable times of the day without accessible means, in order to spend time arguing about the inconvenience and how long it is going to take to be reimbursed for the privilege*. Prior communication of essential information appears inconsistent at best, leaving the main act played out as one of rivalries and personal agendas in order to fill the void of meaningful consultation on the important issues to service users.

So, we wonder why the majority of service user voices remain silent within this process! Why wonder? The only people who can remain vaguely satisfied with this state of affairs must be the *service providers*. Why change, when they can point to evidence that the voices of participation and involvement are a minority of people with different personalised agendas, who do not even agree amongst themselves? The silent majority are more likely to participate in something that is closer to them geographically, which reflects or responds to their needs as they personally perceive them. Not everyone is comfortable with the formality of a structured meeting, or even the informality of a local group. So, for service user

participation and involvement to be engaging and effective for most people requires a range of different options to co-exist. More importantly, to be effective it needs to offer something back to each person who has taken the time to make their views felt... it needs to be actively and sensitively listened to!

It is very difficult to find an agreed definition of what these concepts mean, as they come to assume different things for different people. This then becomes an instant recipe for friction, confusion, frustration, anger and resentment. In turn, these outcomes can potentially be used as *false* evidence that service user involvement doesn't work. In reality, it should be a powerful and effective mechanism for supporting change and good practice across the local services... if we can agree what the concepts mean. Participation and empowerment are two distinct aspects of service user and carer involvement in the planning and monitoring of services. Participation is the process of engagement, where people form a voice and make sure those they hope to influence hear it. Empowerment is the effect of productive participation.

<p><i>Participation</i> is the process, and <i>empowerment</i> is the effect of the process.</p>

They may encompass many functions:

- Statutory consultation
- Participation in local service planning and development
- Information-sharing (inc. sharing personal stories)
- Mutual support
- Campaigning for change
- Combating stigma
- Challenging discrimination
- Raising contemporary issues (e.g. mental health & sexuality, spirituality, mental health promotion, direct payments, advance directives, etc)
- Helping people to 'recover'/stay out of services
- Creative activity
- Advocacy
- Befriending
- Connections with other groups
- Single issue campaigns (e.g. opposition to widening compulsion under revisions to the Mental Health Act, establishing individual rights, biomedical model dominance in services, use of drug company funding, etc)
- Having fun
- Instilling hope

Hope is easily dashed by experiences of distress, so it is essential that the process of participation and involvement does not add to the feelings of powerlessness and hopelessness.

WHOSE AGENDA IS IT ANYWAY?

True participation and involvement is about having a voice, being heard and influencing positive change, with an aim of supporting the development of good practice in mental health services. However, this depends firstly on influencing the agenda to reflect the issues important to service users. Service users are told that they *do* have a say in dictating the agenda, but for them it often doesn't feel like it. The main agenda seems more often to be set by the Trusts; service users then have varying degrees of say in the smaller agenda in response to the preset issues. The service agenda is strongly felt to be over-riding the service user agenda. The services dictate the style and structure of the meetings, including dress codes and perceived etiquette that should be followed.

Powerlessness in the setting of the agenda, or having an accurate historical representation or reflection of your views and experiences is not isolated to the field of mental health alone. Issues of power are at the centre of most struggles. Sinclair (2003) eloquently highlights the plight of the Tiger Bay community in Cardiff's dockland regeneration. In the present debate around the meaning of multiculturalism in the UK a vitally important example of the world living in relative harmony within a local community for well over a century seems to be lost on the post-industrial generation of developers and thinkers. Worse still is the narrow sensationalist and thus inaccurate media portrayal of the community, seemingly as a justification for condemning it to history. When people with real experience and ideas lose a voice we all lose an important message and a part of our potential. The agenda only serves the needs and views of the most powerful, who are often those with the least relevant experience.

In mental health services the travesty is that so much time is spent in reactive mode rather than proactive mode. Frustration and anger at the illusion of power leaving participants with nothing better to do than argue about travelling expenses, express concerns about information not passed on effectively, on developing constitutions for ineffective over-wieldy burdensome meetings, and on personality clashes. Service users can flourish and confidently set a constructive agenda that will make a difference, provided that the organisational support is delivered through a 'we are all in this together' approach. *Divide and rule* appears to be the more prominent reality experienced by many.

The Silent Majority

A consistent theme has been the need to attract new faces into the process, and to hear the voices of those who have not been able to engage with the structures in place. Are we taking a very narrow view of what successful service user participation and involvement is (i.e. hearing the majority of voices) through the *current structures and agendas*, or should we be more open and expansive in our vision of what participation and involvement should be about?

There are many obstacles to engaging new faces to voice their opinions:

- Their agenda may be more at the personal level, what is happening for me through my care plan?
- Trust-oriented meetings and being on interview panels may be beyond the comprehension of someone struggling with their own experiences of stigma, poverty and distress
- The priority is to get yourself right, not just attend meetings about other issues
- A consequence of the structure itself (e.g. where you have to be a member of a recognised local forum before you can attend various meetings)
- Not feeling assertive enough at present to make use of the opportunities currently available, having to run the gamut of fitting into the forum's way of doing things
- The lesser geographical accessibility of some forums
- Not having access to or confidence in the use of technology for communicating views
- Not wanting to get caught up in a situation of having to live and breath mental health all the time
- Young people not wanting to accept the service user label
- The fear that speaking up will mean losing your services!

Chemistry and charisma play their own part, in that people will go to places and/or communicate with people who make them feel comfortable and accepted; whereas they will steer clear of experiences that they find unnecessarily challenging or unpleasant.

IS TOKENISM ALIVE & KICKING?

Phrases such as *working in partnership* and *power in decision-making* are seriously called into question. For some the experience is more a *do as we say* approach dressed up as participation and involvement, with virtually no power and control within important decisions for improving practice within Trusts or other organisations. The previous issue of services setting the main agenda, with service users merely in a position to react to it, is one example of tokenism in practice. People have a voice, but only an *illusion of power*.

The process is largely run through committee-style structures, with committee skills and interview skills the highest priorities for training. These are the needs and skills required by the service perspective on participation and involvement. The result is that service users are required to *get up to speed* in the areas of expertise already possessed by service providers and commissioners, in order to be able to engage within the established structures. Hardly a position of strength from which to *lead* on the agenda.

It can ultimately be experienced by service users as a *tick-box* exercise in service user participation and involvement by Trusts and other organisations. Consequently, service users acknowledge they end up fighting amongst themselves over ideas and experiences as a result of the lack of *real* influence.

'Us and Them'

Meetings are generally not positive experiences for most participants, and clashes of many different types emerge. The question is whether these are the result of the reaction to powerlessness, or a natural part of people coming together to challenge each other on the way forward on complex issues. 'Us and Them' is often a strong feeling of division between service users and service providers. However, it can also be strongly evident between service users themselves, with the potential to undermine any claims that they should be given the opportunity to develop their independent service user agenda. Yet differences of opinion expressed by different service providers and/or commissioners are not necessarily seen in the same way... this is debate.

The issue of 'personalities'

Passion for a cause is vitally important, but not when it is *blind* to the views of others around you, and actively excluding the participation of others *on the same side*. Some people disengage as a result of the experience of being patronised or shouted down by other service users, or the experience of feeling unable to compete with strongly driven personal agendas dressed up as the views of the majority. *Challenge* develops better decisions, but *conflict* generally serves to switch people off. Some also fear that the majority become tarnished by the views of the few. Active listening is a skill required of the professionals, but an equally important skill for individual and groups of service users to develop if they want to have a chance of constructively influencing the process.

Threats and fears

Can some service users seriously have the services they need and use withdrawn as a consequence of their participation and involvement? A danger is that if you attend high level meetings in the hope of contributing your experiences to the process of change you may be considered to be functioning well enough not to need the services you are currently receiving. Even worse, if you subsequently do need referral to or increase in particular services, will you be labelled as *difficult* because you are actively involved in the service user movement?

If we treat active service user involvement as a reason for reducing support we are only contributing to an unnecessarily restrictive approach to the whole process. We are saying one of two things:

- Only *very well* and *robust* service users are worthy of being listened to
- We are failing to accept that all people have potential if given appropriate encouragement and support.

Nobody by right would choose to be a service user, but having had the disposition placed on them many people have reacted with a passion and considerable talent to demand to be heard. A tremendous strength and resource is the determination, imagination and ability of so many people. It is the Trusts that should be in the reactive position, responding to a dynamic mental health agenda set by the very people the services are meant to serve. However, this potential remains unfulfilled; partly undermined by the lack of any unified agenda agreed by the diverse voices.

TRAINING: POTENTIAL OR WASTE?

The influence of so much of the training agenda becomes focused on the skills required to engage with the needs of Trusts and other organisations (i.e. skills for attendance at meetings, being on interview panels). One argument is that service users are not openly asked what training would support *their* own agenda priorities and needs, so the focus rests with a need to improve their personal confidence within the reactive role. Is the issue just poor communication of the opportunities or linked to a deeper concern for the lack of influence on priorities?

More effective use of resources requires a coherent plan linked to a better developed agenda. When asked openly, *interviewing* and the confidence and assertiveness in *committee skills* have been raised by service users as training needs, but is this more out of a need to meet a predetermined agenda? The wider range of ideas I have encountered in conversation with service users raises significant insights into a broader agenda:

- Assertiveness to build confidence and self esteem
- Personal recovery skills
- Self management through 'expert patient' training
- Positive risk-taking
- Things that would help you to help others
- Media awareness training
- Presentation skills (to help us get our message across more effectively)
- Audit and monitoring/review skills
- Research to help influence what underpins quality services
- The law of 'entitlement' to services
- Planning skills
- Strategic thinking
- How to visit and befriend people... making contact and engaging views
- Developing options for 'sanctuary' (alternatives to current crisis options)
- Reaching out to the public

From the opposite direction there is the issue of service users being involved in the training of others (e.g. presenting the service user view on training programmes for professional student's courses and post-graduate training events). The identified value of this type of initiative is through gaining accessibility to people early in their training or post qualification experience, telling them how it really is rather than the academic approach enshrined in the content of most courses.

Training through a piecemeal process of separate initiatives achieves little of strategic value for promoting better service user participation and involvement, but serves mainly to meet the objectives of the organisations, as well as more personal gains for the individual. More effective use of resources requires a coherent plan linked to a better developed agenda.

AN AGENDA FOR CHANGE

Trusts do employ talented and experienced people, but they should be more open to embrace and learn from the service user agenda if the real meaning of *partnership working* is to be achieved. The *illusion* of power and control is a deception which only serves to breed anger and frustration. This negativity inevitably results in criticism of what others do in the name of service user support, even to the point of in-fighting amongst service users themselves. Confidence and improved self esteem come from having opportunities to influence and control the process; to resolve conflicts positively and constructively; and to set the agenda based on real experience and priorities. This applies as much to service users, managers, practitioners, commissioners and volunteers.

The rhetoric of social inclusion, focusing as it does on employment and meaningful activity will not be fulfilled unless we can develop real opportunities for people. Contracts for developing service user participation and involvement should be largely ring-fenced as supported employment opportunities for service users. However, confidence is not built on opportunities to flounder and fail; so adequate guidance, support and safety nets are essential to promote the greater potential for achievement and success.

There is some merit in *professionalizing* the approach. Both in terms of raising its profile and respect for what service users have to say, and to give recognition to the skills, abilities and commitment of all involved. I recognise that the benefits system continues to be a major barrier to enabling service users to achieve their real potentials, and we would have to consider ways and means of adapting the system to enable some of the following recommendations to be fully realised. As suggestions for action they set out a vision of how effective service user participation and involvement may be achieved at a local level. It is not a one-size-fits-all approach. Different people have different ways of engaging their

views and ideas into a process, which requires a mix of methods for engaging them most comfortably.

- A more focused and strengthened structure:
 - Area-based forums; elected to engage and articulate the independent agenda.
 - Local forums; responding to local needs of groups and the less well engaged individuals.

- The area forum to be made up of elected service user representatives:
 - Short-term renewable contracts for part-time paid/voluntary work (dependent on the impact of the benefits system).
 - Elections to be by secret ballot with each candidate presenting their personal manifesto (c.f. political process).
 - The roles of this group will include:
 - Meeting on an agreed frequency (e.g. monthly).
 - Each member to nominate their own *mentor* (for advice and support, but not to attend the meetings).
 - To establish and develop the details of the independent service user agenda.
 - To invite specific individuals to attend/present to the group on particular issues of expertise.
 - To manage the total budget for running the activities (including providing an annual statement of activity and accounts, with necessary support and guidance).
 - To regularly visit, consult with and disseminate information to all local forums (and support areas where local forums are not well established).
 - To meet with and liaise with Trust staff, commissioners, carer's representatives, voluntary agencies, in the business of developing and communicating the service user agenda.
 - To develop and manage specific service user-led projects (including engaging other service users and others, as appropriate).

- A small group of non-service user observers of the area-based group, to monitor and advise on its work (but not with decision-making powers on the shape of the independent agenda).

- Local forums to develop functions and services that reflect local needs and talents, and to be creative in ways of engaging the voices of those who do not readily fit into the more formal structures.

- The role of the Care Services Improvement Partnership (formerly Development Centres) & NIMHE is to support the process, lobby others to

the same aim, as well as strengthening service user involvement in their own activities as planned.

- Role of allies (managers and practitioners) within Trusts to be personally responsible to make contact with the area-based group and/or local forums to offer their support, expertise and interest for service user participation and involvement.
- Developing a coherent training plan that reflects the *needs identified by service users* in relation to the independent agenda established for participation and involvement.

References

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