

Voices Of eXperience

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GOOD PRACTICE IN SERVICE USER INVOLVEMENT GUIDANCE NOTES-MAY 2007

1. INTRODUCTION

The principle that service users must be involved in the development, and review, of both their own care and treatment, and in Services and Systems, is now well recognised in Policy and Legislation. Some organisations are more committed to ensuring that this becomes a reality than others. However, most have requested some guidance in this area.

This document is not to be seen as definitive guidance, but a collection of the views of many Scottish mental health service users and people with a lived experience of mental health problems. VOX have developed this document to illustrate some of the considerations and requirements which should be taken into account if effective service user involvement is both to become more widespread, and if it is to achieve the desired outcomes for all those invited to participate.

2. PARTICIPATE/ INVOLVEMENT - WHAT DOES THAT MEAN?

In addition to participating in our own care, treatment and service and system planning, service users are increasingly being considered for "participation in" - by that we mean carrying out - research, training, leadership programmes and many other areas of involvement with people and organisations from both the public and the voluntary sector. Some service users are, or may become,

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involved as individuals, contributing their own personal experience of mental health problems and recovery.

Some may represent Patient Councils, Collective Advocacy Groups, Local/Regional/Diagnosis-specific or Service -specific groups etc.

However, it has to be acknowledged that, in the past and occasionally still, some attempts at service user involvement are limited, at best, and tokenistic, at worst.

It is essential that service user involvement and participation is real and meaningful, and is based on empowering the individual to regain more control over their lives, develop their capacity, confidence and self esteem, allowing and facilitating their participation as citizens in both their own lives, and in helping to contribute positively to improving the lives of others.

3. GETTING THE BEST FROM SERVICE USERS

It is vital to ensure that when we are active in this way, we are not seen as "trouble makers" and that our views are given due respect and cognisance. We may often require additional support to be involved in meetings, committees, policy/service review groups, projects etc. as will be described later.

Our views should never be invalidated by claims of being "unrepresentative" just because we may be more or less articulate or tenacious than others. There is no such thing as a "typical" service user.

If there are no groups in the area to enable a service user to have both support and a natural constituency, consideration should be given to funding, and supporting the development of one. The

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exchange and sharing of ideas, views and experiences is fundamental to the success of an active service user.

There should be clear procedures for, and expectations of, all members of any group, meeting, committee etc. For example-how do you make a point during the meeting-raise a hand, raise a card, just catch the Chairperson's eye etc? What are the rules of operation?

There should be clear aims and purposes and it should be apparent as to how the subjects considered bear a direct relation to our lives. We require clear ideas at the outset of the issues, consequences and impact of these subjects being considered.

It goes without saying that we should be involved, in all initiatives, at the earliest possible opportunity in order that our influence is consistent throughout all processes and we share the feelings of true ownership and effective influence over the outcomes.

Consideration should be given to contingency plans, in respect of all those involved, but including particular consideration to ourselves, if any member of the programme becomes unwell and is either unable to continue, or has to take a step back in the degree of their involvement. It may be pertinent, for example, to involve two service users for both support and to address imbalances of representation in meetings. (It can be intimidating to be the lone service user voice in a room full of professionals!)

If there is a training programme to be offered to all participants, this should take account of the particular needs we may have. It should include our particular support needs and be aimed to build our capacity to effectively contribute.

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If there is to be payment for our contributions, this should be done in an equal way with other participants, but take account of any potential effects on our benefits, if that is our circumstances. Contributions could be considered to the group that we may be representing, in order to support, and build further capacity for future engagement and participation.

Even if no payment is to be made, it is important that there is a process to repay all expenses, on the day or even in advance, if this is possible. Not all of us can wait to get the monies recompensed some time in the future and some of us would not have access to sufficient funds to pay expenses on the day of the event.

Expenses should be offered, rather than us having to ask, or remind those responsible. Consideration should be given to other incentives such as good catering, availability of Lunch and the possibility of social events which involve the group/project members in a social context, in addition to the purely "professional" relationship.

Regular breaks should be incorporated into meetings, and events, and flexibility considered in the areas of timescales, availability of resources, working practices and expectations.

There is a major and quite fundamental issue about accessible language, acronyms and jargon. For truly effective participation, this should be minimised in both documentation and conversation to aim for ease of understanding. There needs to be time available for participants to stop proceedings for explanation and clarification of terms with which they may not be familiar.

It has to be recognised that there is a "language gap" between professionals and the public. And, of course, this is exacerbated if

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you have a communication difficulty, or if English is not your first language.

Issues of diversity need to be taken into account, we are as diverse as the general population and the involvement of particularly marginalised groups, in all communities must be encouraged.

Written information needs to be distributed well in advance of meetings, with any requirement for responses clear, in order that, it may be read, understood, explained-if necessary, digested, considered, a view taken and this communicated in the appropriate manner. Consideration should be given to the accessibility of fonts and formats of all printed materials. Not everyone has access to, or can afford, computers, e-mail and printers-so this should be considered in order that such an individual can receive papers by "snail mail".

It should also be appreciated that we may want to consult with our grass-roots constituency; this takes considerable time and effort if it is to be achieved effectively.

With reference to the time which may be required for explanation and clarification, there is also a requirement for simple time and space to enable us to make our contribution. This is very often underestimated and ignored in the pressures of deadlines and diaries. A pre-meeting or post-meeting with the Chairperson may be useful, either in person or over the phone, in order to give service users further opportunities to contribute to agendas or clarify contributions made.

Verbal communication, both within and out-with meetings needs to be frank and open, with no exclusive dialogue or decisions being practiced. There also needs to be clarity about how the views collected will be documented, what will happen to them and what feedback there will be on the impact of these views and any

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subsequent decisions taken. Outputs from events have to be made available as early as possible to allow opportunities for reflection.

Attitudes and behaviours can't be ignored and we need to be reassured that we will be given due respect and consideration and that our involvement is seen as valuable, rather than merely a tool for meeting the consultation needs of service providers, authorities or Government. The engagement needs to be in a non-threatening and accessible environment with an open, accepting atmosphere.

We also find it encouraging if our contributions are acknowledged both verbally by the Chairperson, e.g. "That's an interesting point" e.t.c. and by inclusion in the minutes.

If necessary, Chairs and vice-chairs of meetings, facilitators, leaders etc should undertake training in involvement and participation. We also appreciate being shown gratitude for making, what in many cases is a voluntary contribution and effort, to the successful outcome of projects and programmes.

Consideration should be given to those of us who have caring responsibilities and who may need to make arrangements, and perhaps be recompensed, for the alternative provision of care to our loved ones.

Methods of involvement are varied and it is recommended that approaches are used across these possibilities to engage people using a diversity of possibilities. These include: questionnaires, feedback cards and suggestion boxes, talking walls, video boxes, e-mail, web fora and blogs, chat rooms, interviews-with a variety of structures, discussion groups, focus groups, service user groups, service user representatives, service user events and conferences, music, drama, writing and other arts.

4. CONCLUSION

In conclusion, Service User involvement in Mental Health is clearly desirable both for those carrying out functions as part of their employment and for our personal development, knowledge, confidence and feelings of self worth. In addition to the undeniable fact that we are in a unique position to be able to influence the future direction of services, systems and policy, due to us being the experts by our own experience of mental health problems. To enable future involvement to be sustainable and meaningful, we recommend that the areas mentioned in this document become fundamental to the planning for such involvement.

We believe we should all have this opportunity to be involved to the extent with which we are comfortable, and if we desire to make a difference.

If we agree to take part, it should be an experience of mutual benefit, which is enjoyable and worthwhile and in which we are given due respect and value. It is our right as citizens to have these opportunities and we hope that this document assists, in some ways, towards this right becoming a much more widespread, and effective, reality.

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Information/Involvement/Influence-VOX aims to develop a National membership organisation of, for and by people who have experienced mental health problems, which will drive policy and practice, facilitate partnership working and strengthen our voice.

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Statement: We would like to thank all of the individual people with experience, and their groups who helped both contribute to, and inspire this document.

We are happy for it to be photocopied and distributed widely, however we would appreciate it if you could drop us an e-mail to let us know whether you are using the document and whether you found it useful.

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