

## **User Involvement: A Brief Literature Review**

### **Introduction**

This is a brief literature review, with reference to further reading. I have tried to list as many key references and new (to me) references as I can, and then to explore a few of these in more detail. I have chosen a few useful resources and a few literature reviews to explore in more detail, in order to help us to benefit from the work of others. I have also focused on the practical rather than the theoretical as it seemed to me to be a more useful thread to follow. However, there are many more useful texts on the subject of 'service user involvement' in mental health, on empowerment, social inclusion and recovery and so on, some of which will refer to user involvement in passing. For example, a literature review on 'Implementing a recovery approach in policy and practice' by Kathryn M. Berzins is to be found on the Scottish Recovery Network website. It includes a side and a half of discussion with reference to 'service user involvement'.

The documents I have considered in detail are as follows:

1. 'How managers can help users to bring about change in the NHS' SDO Briefing Paper 2004: reviews two literature reviews
2. Good practice guides on user and carer involvement written by TwoCan Associates with LMCA
3. 'Hear by Right' National Youth Agency resources for involving children and young people (includes self-assessment tool)
4. 2007 literature review on 'empowerment, employability and service user involvement' Scottish Poverty Information Unit Service User Involvement Project.
5. SURGE 2005 Guidance for Service User Involvement in the Mental Health Research Network.
6. Welsh Assembly Government: Stronger in Partnership 2 – Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales, October 2008
7. Kalathil, J. (2008) *Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement*. National Service User Network in collaboration with Catch-a-Fiya
8. Robson P, Begum N and Locke M. (2003) *Developing user involvement: Working towards user-centred practice in voluntary organisations*. York: The Policy Press in association with the Joseph Rowntree Foundation
9. Wallcraft, J., Read, J. & Sweeney, A. (2003) *On Our Own Terms: Users and survivors of mental health services working together for support and change*. London: The Sainsbury Centre for Mental Health.

The different documents take slightly different approaches or bring different perspectives to the issue of involvement, but there are some significant common themes. These include:

- The importance of **clarity and transparency** in communications with people – about the nature of involvement, the potential for influence in a project, and so on.
- An openness to **change** is vital if involvement is to be meaningful.
- The importance of having a **clear purpose** for involvement.
- The importance of involving people at the **earliest possible opportunity**; this can avoid misunderstandings and maximise the benefits of involvement.
- The value of providing **adequate support** and **appropriate training**.
- The importance of allowing **sufficient time and resources**.
- The importance of ensuring **accessibility**, both physical and language-related.
- The value of allowing **flexibility** to enable a range of people to participate and to overcome or work through periods of distress.
- An acknowledgement of the need for **diversity** is vital; human beings are highly diverse, have a wide range of different experiences and come from different communities. Particular consideration needs to be given to involving people from black and minority ethnic communities, and people in forensic services, for whom involvement is less easily accessible.
- This means adopting a **range of different approaches** to user involvement – not a ‘one size fits all’ approach.

Document No.1 is a useful summary of two literature reviews, bringing together the learning from both of these to highlight common themes about what helps to promote successful user involvement. No.4 is also a literature review, but with a different slant as it focuses on employment and empowerment. Documents 2 and 3 both take a more practical approach, with guidance for good practice illustrated with case studies; no.3 gives an example of a self-assessment tool, which may provide a useful template. Document 6 also gives a checklist and monitoring tool for assessing progress against standards for involvement. Document 8 speaks directly to our central ring; it usefully distinguishes between ‘user-centred’ and ‘management-centred’ user involvement. The authors favour the former, in that it enables service users to gain greater independence and freedom to develop their own priorities. Document 7 looks specifically at the barriers and facilitators for involvement of black and minority ethnic service users, with reference to consultations based on the lived experience of service users. It gives recommendations for effective involvement, both for NSUN specifically and, more broadly, for other individuals and organisations. Finally, document 9 speaks directly to rings 3 and 4: the user/survivor movement and user involvement in services; it is an excellent report and well worth reading.

## **Nine documents in detail**

### **1. *How managers can help users to bring about change in the NHS* Briefing paper March 2004; NHS SDO R&D Programme**

This briefing paper summarises two literature reviews which examined the best ways of involving service users. The first of these studies was by Mike Crawford, Deborah Rutter and Sarah Thelwall of the Department of Psychological Medicine at Imperial College, London. It aimed to “*review literature on user involvement in change management across a range of sectors in order to identify factors that promote successful user involvement*”. The second was by Diana Rose, Pete Fleischmann and colleagues at the Service User Research Enterprise, at the Institute of Psychiatry, London. It examined “*literature about user and/or carer involvement in managing organisational change within mental health services*”, a field of health care in which user involvement is already well developed. These are the principles highlighted at the front of the briefing paper, drawing on both of these reviews:

- Have a clear idea about the aim of involving service users before inviting them to get involved.
- Be honest with service users about the potential for change, particularly if the options are limited.
- It is not difficult to find out what people want; the difficulty is in achieving change.
- One of the main obstacles to involving users can be the reluctance of health professionals such as doctors and nurses to embrace change suggested by service users.
- Front-line staff need training to help them appreciate why and how service users are involved, and to carry them along with the process.
- If service users are helping to make decisions about complicated and highly technical services, they will need extra time, information and support.
- User involvement does not stop when users’ views have been obtained; this process must be followed by continuing work to change services based on users’ views.
- Users may need training to enable them to undertake some user involvement activities.
- When involving users, managers need to be sensitive to staff’s perceptions of their own status, and their status differential with their clients.
- The onus is on managers to present information for service users in a way that the users can understand.
- In mental health, user groups that are funded need longer contracts so that they do not have to spend all their time trying to get funding for the following year.

- User involvement is not a bolt-on extra. It is a way of changing the philosophy of an organisation and all the roles within it.

Within the document factors that service providers should consider when planning and implementing user involvement in change management are given based on Crawford et al's review:

1. Be clear about the aims and scope of involvement before contacting service users.
2. Make the aims and scope of involvement clear to users and carers who participate.
3. Ensure that your organisation is committed to acting on the views of service users before user involvement begins.
4. Before embarking on new initiatives to involve service users, find out what has taken place previously.
5. If possible, encourage local service users to express their aims and demands, too.
6. Make sure that you allow adequate time and resources to support user involvement.
7. Consider how to give feedback to service users who participate.
8. Ask yourself how important it is for those service users who participate to represent users' views in general. Using a range of methods of user involvement will help you access a range of views.
9. Ensure that adequate information, time, and administrative and financial support is available for service users.
10. Ensure that the staff of your organisation who are involved in the process of user involvement are committed to making it a success.

## **2. User and Carer Involvement: How to develop a strategy / Sharing our experience / A good practice guide; 3 documents compiled by Kristina Staley and Bec Hanley, TwoCan Associates and LMCA**

This is a really useful resource. It emphasises the importance of clarity regarding *why* you want to involve people, who to involve, where and when, how and what. It takes you through the stages with some examples from different organisations. These are their key points from the Good Practice Guide:

- Give service users and carers a choice about how, when, where and how often they get involved
- Think about the level of involvement you want – consultation, collaboration or user control
- Ensure you involve a wide range of people – make special efforts to involve people who may often be marginalised

- Provide training and support for service users, carers and staff – think about expenses and payment, training, access issues, information, involvement in meetings and emotional support
- Ensure user and carer involvement has an impact
- Keep all stakeholders informed of the success of user and carer involvement
- Involve service users and carers in measuring the impact of user and carer involvement

### **3. 'Hear by Right' and National Youth Agency resources for children and young people: (<http://hbr.nya.org.uk/>)**

These resources were developed for involving children and young people, but are easily transferable. They provide another way of looking at things that could be helpful in looking at involvement across a whole organisation. It is useful in that it gives a model for a tool which may be possible for Mind to use or adapt for the future. They propose seven standards (taken from the 7 S model of organisational change developed for McKinsey Consultants in 1982):

- Shared values – at the core of the framework
- Strategies
- Structures
- Systems
- Staff
- Skills and knowledge
- Style of leadership

Each standard has indicators, and requires self-assessment at three levels of performance: emerging, established and advanced. Resources include a book on the standards framework, 'Involving children and young people – an introduction' and a **Self-Assessment Tool** to map and plan participation.

### **4. The Scottish Poverty Information Unit *Empowerment, Employability and Service User Involvement* – literature review, 2007 [www.serviceuser.org](http://www.serviceuser.org)**

This project and review is part funded by the Scottish Executive. This literature review focuses on issues connected with employability and empowerment, as the title suggests. It is not too long and quite readable; I have an electronic copy I can share. One of the elements that they address is 'empowerment' which is a term that seems rarely used nowadays within this discourse. They also focus on the *knowledge* that service users bring to the table: that this knowledge is unique in that it comes from the receiving end of services rather than from the delivery (and, I would add, the management) end of services. Amongst their conclusions is the suggestion that a variety of approaches to involvement is required to

address the range of barriers faced by people using employability services. With their particular perspective on employability, they also conclude as follows:

*It may also be fair to argue that the concept of user involvement, like empowerment and, to an extent, employability, also draws from principles of social justice and especially social inclusion because inclusion can mean not just participation in the labour market but also participation in civil life.*

... which links with the policy initiatives on inclusion/involvement in wider society.

## **5. SURGE (Service User Research Group England) (2005) Guidance for Good Practice: Service user involvement in the UK Mental Health Research Network. London: UK MHRN.**

This guidance document is about service user involvement in research, but once again many of the issues and principles are eminently transferable to other domains. Part I is a literature review of service user involvement in mental health research, from which the following themes emerge:

- Benefits of involvement:
- Power and negotiation
- Clarity/transparency
- Early involvement
- Accessible language
- Flexibility
- Support
- Training
- Payments
- Resources

Whilst some of these themes are self-evident, it is worth looking at a couple in more detail. The benefits of involvement, for example, include consideration of the benefits to the research itself, to the service users and to the researchers concerned. The review found that greater understanding of mental health problems, or of using particular treatments was made possible through the involvement of service users, that new knowledge could be created and that the quality of the research was thought to be improved in some cases. Several papers referred to the potential for obtaining more open and truthful responses in interviews where the interviewer was a service user. A few papers referred to increasing the validity of the findings through having service users involved in designing the questions and, significantly, in the analysis and interpretation of results. Finally, many papers suggested that service user involvement increased and improved the dissemination of research results.

The section on power and negotiation underlines the power differentials in an academic research environment and advocates open acknowledgement of this as well as finding ways of negotiating differences in opinion.

The good practice guidance (Part II) covers some similar themes to other articles and reports, although many of the sections are more specific to research. Part II includes the following chapters:

1. Underlying principles
2. Capacity building
3. Identifying priorities
4. Commissioning research
5. Ethical Approval and Research Ethics Committees
6. Undertaking research
7. Dissemination and Implementation
8. User controlled research

For our purposes, the most relevant sections are probably 1, 2 and 6. Section one covers the underlying principles of clarity and transparency, respect, diversity, flexibility and accessibility. Section 2 recommends capacity building through exploring the local community, building up collaborative relationships over time, identifying a budget and keeping a record of contacts. Section 6, which addresses the practical issues of carrying out the research covers consultation, planning and starting a project (including involving service users from the start), supporting and maintaining a project (including support, training, flexibility and negotiation), and the particular circumstances surrounding the employment of service users.

This last issue may be of some interest, as it touches on the different position of people (service users) who are employed within an organisation as against being 'involved'. The authors point to the fact that employment is a key element of social inclusion, but that being employed and thus subsumed within an organisational hierarchy may mean that their identity as 'service user' is secondary to their identity as employee. This may mean that the particular experience and the views they brought to the job become overlooked or marginalised. In this case, the report discusses employment within an academic institution, but some of the issues will be relevant to any organisation.

**6. Welsh Assembly Government: Stronger in Partnership 2 – Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales, October 2008**

<http://www.wales.nhs.uk/documents/strongerpartner2e%5B1%5D.pdf>

This is another useful and well written document, with the added advantage that it gives a number of case studies of involvement in different organisations throughout Wales. It provides practical guidance and gives service planners and providers the opportunity to declare their commitment to ensuring meaningful service user and carer involvement by adopting a Charter and using a Checklist as a tool to assess progress. In exploring 'why involve people?', this document starts with a consideration of the value of empowerment before identifying the advantages for mental health service users, service planners, providers and society in general.

They go on to suggest that genuine involvement requires building confidence, providing relevant and timely information, providing suitable space and time and responding appropriately to feedback. They detail a number of different ways of involving people outside of traditional form meetings, including Question and answer forums, Questionnaires, Workshops, Blogs, Informal group activities, Social gatherings and Theatre and performance

They also have a section on payments and expenses, which gives some good practice guidance. Section 8 is the Charter and Section 9 is the Good Practice Checklist and Monitoring Tool. This last consists of the following sections:

- Design and Planning of Services (12 indicators)
- Delivery of Services (2 indicators)
- Training (7)
- Expenses and other payments (3)
- Support for carers (2)
- Service users and carers attending meetings (8)
- Monitoring (3)
- Evaluation (1)

Each of these is intended to be marked 'not met', 'part met' or 'met', 'Action taken', 'Monitoring arrangements' and 'Review date'. It might be useful for Mind to look at a similar model for monitoring.

**7. Kalathil, J. (2008) *Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement*. National Service User Network in collaboration with Catch-a-Fiya.**

[www.nsun.org.uk/WebPageFiles/65/NSUN\\_Report.pdf](http://www.nsun.org.uk/WebPageFiles/65/NSUN_Report.pdf)

This report is based on consultations with black and minority ethnic service users about their experiences of being involved, as well as with white British service users who have involved BME service users in various initiatives and groups. The aim was to explore how to work more effectively in collaboration to increase



the influence of service users from black and minority ethnic backgrounds. What is refreshing about this report is the return to basics. Although in some ways it is discouraging to hear that service user involvement has not changed the way in which the mental health system treats people, particularly people from BME communities, it serves as an important reminder of the fundamental purpose of user involvement: improving services for people. Involvement and engagement in advisory groups and committees about the latest jargon-based policy is all very well, but if user involvement has not changed the basic experience of people in services, then we still have work to do. The other refreshing issue this report picks up is the need to link with the wider social agenda; re-visiting the structural inequalities in society and addressing these through a political agenda. The recommendations for effective user involvement are as follows:

- A broader social change agenda – linking with race and rights based initiatives
- Invest in building relationships – between communities and between professionals and service users
- Work with professionals – enable them to think about race related issues in their practice
- Support agendas set by communities at the local level
- Invest in people's potential – turning the focus away from their mental health status
- Develop networking – mobilise support and solidarity through peer groups, sharing learning, etc.
- Mentor new service users – people who may be newly interested in user involvement
- Develop involvement standards
- Monitoring and evaluation – to focus on outcomes

**8. Robson P, Begum N and Locke M. (2003) *Developing user involvement: Working towards user-centred practice in voluntary organisations*. York: The Policy Press in association with the Joseph Rowntree Foundation.**

[www.policypress.org.uk/catalog/product\\_info.php?cPath=10033&products\\_id=464](http://www.policypress.org.uk/catalog/product_info.php?cPath=10033&products_id=464)

This report presents the findings from an action research project funded by the Joseph Rowntree Foundation which ran from late 1998 to June 2000. The project aimed to

- support the implementation of increased user involvement in the governance and management of traditionally structured charities;
- develop and demonstrate methods for the management of change that include users, staff and trustees;

- monitor and evaluate the impact of increased user involvement from user and organisational perspectives.

The authors usefully distinguish between ‘*user-centred user involvement*’ and ‘*management-centred user involvement*’. The former is where service users are able to pursue their own objectives and priorities, whereas in the latter, service users would tend to take part in existing structures. They suggest that greater change and more benefits would be achieved for service users through user-centred user involvement, although both might enhance an organisation’s reputation. Features they found to be associated with genuine and sustainable change (i.e. in developing and sustaining user involvement) were:

- Belief in, and commitment to, a user-centred approach
- Facilitative leadership style
- Good quality communication
- Commitment to work with difference

They also found that organisations with a clear commitment (usually over many years) to one clearly identifiable group of users or constituents seemed to be better able to develop comprehensive user involvement. Nevertheless, even if all of these facilitators to change are in place, the authors emphasise that achieving real and sustainable change is slow and needs consistent pressure over time. The report has chapters on the facilitators and barriers to change, and gives a number of useful case examples.

### **9. Wallcraft, J., Read, J. & Sweeney, A. (2003) On Our Own Terms: Users and survivors of mental health services working together for support and change. London: The Sainsbury Centre for Mental Health.**

This is a seminal report, and makes essential reading for anyone who is interested in the service user/survivor movement in England and the role it plays in mental health service user involvement. It makes the important point that service user groups exist for many reasons, not all of which are related to user involvement. Nevertheless, some 72% of groups were engaged in some form of user involvement at the time of the survey (attending consultative or decision-making bodies, often to do with the National Service Framework for Mental Health). The report makes some substantial and comprehensive recommendations which fall into three categories:

- A. Building the capacity of the user movement;
- B. Strengthening and developing user involvement in improving services;
- C. Developing a new integrated prevention, self-management, recovery and inclusion focus for all mental health, social care and employment services.

For our purposes, categories A and B are the most relevant, with B in particular relating to the ring concerning involvement in mainstream services. Recommendations within this category include the development of national good practice guidelines for user involvement. Draft principles for such guidelines are given in the report (pp63). Echoing Kalathil's report (No.8) (although in chronological terms, it is in fact the other way round) the authors note:

*“Our findings show that user involvement is a mixed blessing for service users/survivors. While opportunities for involvement in policy making, at least at the locality level, are increasing, there are still many improvements that need to be made if they are to play an equal part as stakeholders. Their role currently, at best, seems to be to share the responsibility for difficult decisions about the allocation of scarce resources **rather than being able to bring about the profound changes they want to see in the ethos of service provision.**”*

[my bold]

## **Some further reading**

Badham, B and Wade H. (2008) *Hear by Right: standards framework for the participation of children and young people*. revised edition 2008. The National Youth Agency. <http://hbr.nya.org.uk/>

Breast Cancer Care *User Involvement Strategy 2007-2010*. (Good example of an organisational strategy)

Campbell, P. (2005) 'Harnessing our energy' chapter in *Beyond the Water Towers* (see below). Sainsbury Centre for Mental Health.  
[www.scmh.org.uk/publications/beyond\\_the\\_water\\_towers.aspx?ID=411](http://www.scmh.org.uk/publications/beyond_the_water_towers.aspx?ID=411)

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Crawford, MJ, Rutter, D, Manley, C, Bhui, K, Weaver, T, Fulop, N and Tyrer, N (2001). *User Involvement in the Planning and Delivery of Mental Health Services*. Report to London Region NHSE.

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Faulkner A & Morris B. (2003) *Expert Paper on User Involvement in Forensic Mental Health Research and Development*. National Programme on Forensic Mental Health Research and Development. (copies available from the author: [alison.faulkner2@btinternet.com](mailto:alison.faulkner2@btinternet.com))

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[www.invo.org.uk/pdfs/Colliding%20Worlds.pdf](http://www.invo.org.uk/pdfs/Colliding%20Worlds.pdf)

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Hanley B. et al (2004) *Involving the public in NHS, public health and social care research: Briefing notes for researchers*. (second edition edited by Roger Steel) INVOLVE. [www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf](http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf)

HASCAS Making a Real Difference: *Strengthening Service User and Carer Involvement in NIMHE*. Final report April 2005.  
<http://www.nimhe.csip.org.uk/silo/files/final-making-a-real-difference-report.pdf>

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NHS Wales. *Signposts Two: Putting public and patient involvement into practice*. (2003) London: Office for Public Management, Cardiff: National Assembly for Wales.

NIMHE/CSIP (2006) *Valuing Involvement: Strengthening Service User and Carer Involvement in NIMHE: Good Practice Guidelines for involving mental health service users and carers*. **\*has good practical checklist for use before and after meetings\***  
<http://www.nimhe.csip.org.uk/silo/files/involvement-good-practice-guidelines-sept-07.pdf>

NIMHE/CSIP (2008) *Valuing Involvement: Making a Real Difference Strengthening Service User and Carer Involvement in NIMHE and CSIP: Payment and Reimbursement Policy Guidance*. **\*very good detail on payments**

**and benefits – but this will go out of date \***

<http://www.nimhe.csip.org.uk/silo/files/payment--reimbursement-policy-guidance-mar-08.pdf>

Robson P, Begum N and Locke M. (2003) *Developing user involvement: Working towards user-centred practice in voluntary organisations*. York: The Policy Press in association with the Joseph Rowntree Foundation.

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Time to Change: resources at <http://www.time-to-change.org.uk/>

Wallcraft, J., Read, J. & Sweeney, A. (2003) *On Our Own Terms: Users and survivors of mental health services working together for support and change*. London: The Sainsbury Centre for Mental Health.

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