

The development of service user initiatives in an inner london borough

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Abstract: *This paper describes the journey of a social services manager taking on the development of an over-arching user involvement strategy within an integrated mental health service. It highlights the introduction of a framework for user involvement which has proved able to adapt to successive policy initiatives including the Health and Social Care Act, Changing the Balance of Care, Patient and Public Involvement, and most recently Personalisation. It discusses some of the challenges, but also the real benefits of meaningful service user involvement. It also suggests that managers with a social care background are uniquely positioned to take on such a development.*

Key words: *User involvement; Involvement register; Self-directed support; User focussed monitoring; Personalisation.*

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Background

In 2002, I became Head of Social Care in the Integrated Adult Mental Health service in Southwark, and as part of the portfolio of responsibilities that came with the post, there was a lead role for developing services for mental health service users involvement. This was not a completely new area for me, as I had in the past spent a lot of time, when a CMHT manager, liaising with local user groups in North Southwark in order to develop a new day service which would reflect a greater level of service user influence or direction. The concept of enabling self determination for clients was something which was embedded in the social work literature I had grown up with, although it was harder to find models where the idea had been systematically implemented. The specification we developed for the day centre included involving users in its daily management, and in contract monitoring meetings for the service. I suspect though that for the new post, I was no different from many managers asked to take on such a role, in that it came with no very clear brief on how to take the task forward.

It seemed to me that the most crucial aspect of developing service user initiatives was, and is, that they should be part of a wider strategic plan to enhance user involvement across the spectrum, and not just focus on service user groups - the most traditional, and at the time, most recognisable, form of user involvement. In 2002 there were a number of local service user groups in the area, but they only seemed to be loosely allied to a wider movement, and the local Trust (South London and Maudsley NHS Foundation Trust), tended to consult with its own in-house group of service users at the time. This left large numbers of people who would perhaps have liked to be involved in services, but who did not necessarily want to be associated with an identified mental health group.

At this time, the concept of Patient and Public Involvement (PPI) was beginning to take off, in the wake of the closure of Community Health Councils, and the development of Patients' Forums, but once again this latter form of involvement tended to be circumscribed, and limited to a few activists. Nevertheless, the climate for developing user initiatives was changing, with the Government's Paper, 'Shifting the Balance of Power,' (2001) and the development of the concept of patient choice, both helping to raise the profile of user involvement with senior health colleagues, whose initial reaction to user involvement had been lukewarm.

'Shifting the Balance of Power' was radical in concept, but needed to be radical in reality as well. Translated into thinking about user engagement it meant behaviour needed to change throughout our joint organisations. These policy announcements had provided the impetus to focus more on enabling and supporting people, and less on maintaining hierarchy and control, but we needed to actualise this.

The Government could not have been clearer that their reforms were intended to give patients a greater voice in the running of the NHS. They were to become active partners in their own care, receiving more information so they could make more

informed choices about their own treatment, and by extension, about the wider health and social care services they were receiving. In terms of PPI, this also meant local communities were being invited to become involved in strategic planning and decision making to ensure that the NHS was as responsive as possible to patient experience. Section 11 of the Health & Social Care Act 2001, introduced the duty for health organisations to consult on major changes to services, again providing an impetus to user and carer involvement (Department of Health, 2001). Taking this to its logical conclusion, it seemed I had arrived in post at a time when we should be looking at user involvement within almost every aspect of the Trust's activity.

In order to achieve this, it seemed to me that we had to balance two competing demands. It was important that any proposed structure should be able to accommodate existing service user groups, whilst at the same time providing involvement opportunities for those interested in being involved in services in other ways. But equally as an integrated mental health service, we also needed to have a recognised umbrella group locally, which was accepted by all agencies and user organisations as representing a central, or starting point, for user consultation and engagement, whilst developing ways of reaching other service users' views.

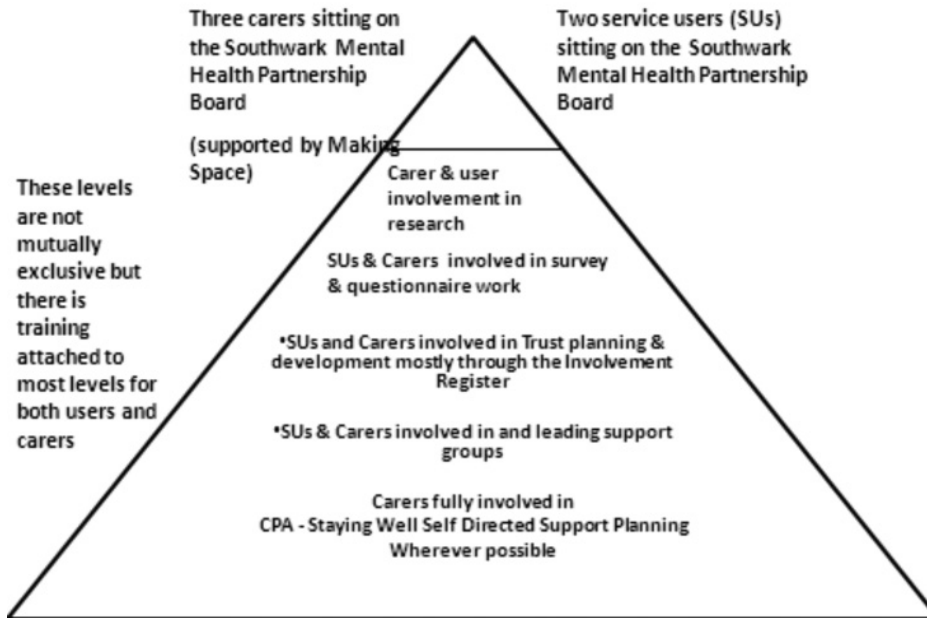
Local structures

Figure 1 overleaf was the structure which was adopted to provide an overview of user and carer involvement. There will always be arguments about how representative umbrella groups are, or can be, but after some initial discussion about whether to choose the Trust based group or an independent user group, it was decided that Southwark Mind would be chosen to provide the overarching co-ordination of user groups.

Southwark Mind run a User Council which has 15 places funded by the Primary Care Trust, and the user council members each represent one user group or day service. The Council then elect two members to sit on the monthly Mental Health Partnership Board. In a reciprocal arrangement, myself, the Director of the local Trust service and a representative from the PCT Commissioners attend the User Council monthly. During the years of the Mental Health National Service Framework, the Partnership Board also served as our Local Implementation Team (LIT). This framework has provided the bedrock from which a number of other initiatives could develop. The User Council was able to disseminate documents we wanted to consult on, to local user groups and day services, and they were then able to provide commentary on these developments via their two council representatives.

Initially there was a degree of caution from the User Council about 'getting into bed with the enemy' but the view we took was that if they were not part of the discussions, it would be more difficult for them to influence decisions, and we would

Figure 1



be happy for them to reserve the right to campaign against any changes they were opposed to. Clearly such a partnership is easier to manage in years of funding growth as opposed to ones of retrenchment, but the Partnership arrangements continue to involve representative users in the current difficult times.

At the poles of user engagement, there are potential disadvantages both to having a user group which is perceived as 'tame' or in the pocket of statutory services, and equally ones which are seen as 'obstructive.' The view which we have taken locally, is that whilst it is important to build service user involvement within your local Trust, it is also crucial to have influential user voices as part of the wider local service economy outside the statutory organisations. Over the past decade Southwark Mind has played a crucial role in the campaign to implement single sex wards; in ensuring that the planned closure of the hospital based psychiatric emergency walk in clinic, included a more carefully thought through replacement with the local Acute hospital A&E; in taking on the Mental Health agenda of the local LINK; in challenging the local charging regime; and in promoting a range of services for BME service users. Whilst not all of the above have been positive from the Mental Health Trust's point of view, the value of having a coherent critique of Trust plans from outside the organisation has been important.

Further development of local groups

As I became more involved in this work it became clear to me that most existing user groups in the Borough were not funded by the PCT or Local Authority, and that different clusters of users wanted to develop new groups and we needed the capacity to help support them grow. Initially I did much of this work, which involved helping groups to seek funding, helping them to arrange premises, and advising them about their structures (Hervey, 2008,a). Two of the newer groups were arts based, Creative Routes and Cool Tan Arts. Both had charismatic leaders, and were able with support to access a range of local mainstream arts organisations, in and around the South Bank (National Theatre, Tate Modern, Young Vic, Blue Elephant Theatre). Owing to the wider Government policy on social inclusion they were now pushing on an open door, whereas some years back, approaches to these organisations would not have met with such a positive response.

Several of these groups were explicitly made part of our Mental Health Promotion Strategy. Among a number of projects which could be mentioned, Creative Routes developed an annual street festival called 'Bonkersfest,' which at its height was attracting 6,000 plus local people. Some staff could not understand the use of what they saw as stigmatising language, not understanding that in line with similar groups such as Gay Pride or Mad Pride, the aim was to take hold of other peoples' labels and show them up for what they were worth. Another group, Cool Tan Arts still runs a very successful series of guided 'healthy' walks across the Borough, called the Largactyl (sic) Shuffle, which now have a national profile. If you type Largactyl into a Google search engine, when you get to the c, the second option offered you is the Largactyl Shuffle. This project attracts up to 70 people to its walks, a mixture of users, carers and members of the general public. The development of these projects has helped to promote a great deal of mutual support within the user community locally, and together with a third group called, Mental Fight Club, they have formed a significant part of our overall mental health promotion work to the local community. Mental Fight Club carried out several pieces of work across all agencies to raise awareness of suicide risk and the fall out from a successful suicide (Hervey, 2009).

Involvement register

As the pressure of supporting so many different groups grew, I decided to seek funding for a User Involvement worker to help develop the strategy. In particular I was aware that although we had a number of local volunteering schemes there were few opportunities for paying service users for their time, and although the Trust had some users involved in its activities, this was, with a few exceptions, mostly fairly tokenistic. Once a worker was appointed her work plan was constructed to encompass

both continued support to external groups, and the development of a much more robust system of user involvement within the Trust's service in Southwark. In relation to the former, she proved notably successful in bringing in money from bids, but her appointment was also a major factor in widening the base of user involvement in the Trust.

By this time we had an Involvement Register in place, thanks to work done by a member of staff in the Trust's **D**eveloping **O**rganisation and **C**ommunity unit. This allowed us to pay service users at different rates for work done on behalf of the Trust. However, although all the paperwork was in place, not everyone embraced this system initially, but we set targets to recruit up to 30 users per annum onto the Register.

In order to create a culture in which user involvement was seen as routine, it was essential that it was embedded in as wide a range of Trust activities as possible. We set about drawing up a plan which initially involved ensuring that each of the four main community teams started to develop a process for engaging users in their locality, using the register. Currently most have a user group, and a carers group, an information area in reception, and have involved users in the planning of their individual services.

Once we had created this capacity to support the extension of user involvement we realised that we also needed to encourage managers to create involvement opportunities for users to take up once recruited. Also the poor experience of one or two users when utilised by some managers, in recruitment for example, where they felt their role on recruitment panels was fairly tokenistic, forced us to revisit good practice in working with service users, and led to the creation of guidance for managers when involving service users in their services. Gradually though they began to recruit their own service users onto the Register. The manager of the Home Treatment Service, for example, recruited three of his own service users to run an audit of users' experience of using home treatment.

As use of the Register expanded, we were also forced to think about developing the profile of each service user so that the Human Resources staff running the Register knew what skills each person could offer. We also began to help the service users think through their own goals in being on the Register, and from a social inclusion perspective, of career pathways which might lead them eventually back to employment and out of the Trust. Logically it also meant that where service users wanted to expand what they could offer, we needed to scope their training needs and to set up opportunities to meet those needs.

Other initiatives using the involvement register capability

The creation of this initial capacity has led to the development of a number of other initiatives, some of which have been picked up by the Trust for wider implementation, since a Patient and Public Involvement lead was set up for the whole organisation. The most notable example has been that we took the early research work done by Diana Rose at the Sainsbury Foundation, on User Focused Monitoring, to pilot a project with Southwark Mind (Rose et al, 1998). This involved training a group of service users in the use of an electronic handheld device (PEDIC – Patient Experience Data Information Centre) to administer a questionnaire to a cohort of patients coming through two in-patient wards and a Home Treatment Team. The recommendations of this study, which were analysed by the service user leading the project, are still being worked through. The most notable of which are

1. a scheme in which some service users have been trained to deliver an awareness training programme to ward staff focusing on how service users perceive the service and on some of the local issues identified as causes of complaints, such as nurses entering patients' rooms without knocking.
2. a service user led survey of attitudes to food on the wards, which has led to much closer user led communication with the Trust's in house catering contractors.

The Trust is now creating a Data Information Centre for co-ordinating all user feedback and we hope that increasingly patients will be involved in analysing these performance metrics, which form part of the Chief Executive's monthly performance meetings. (Hervey, 2010)

The Register also enables us to access a wider range of service users than before, for the sort of tasks that a smaller select group of service users have always been asked to undertake, such as being involved in the reviewing of job descriptions and recruitment, in assisting with certain key committees such as Governance, Police Liaison, new service developments etc. From an initial position in which many managers were antipathetic to user involvement, many now routinely consider user involvement from the inception of projects

None of the above is to suggest that the introduction of these initiatives were without tensions. Some of the existing user groups saw the broadening of our user involvement and wider consultation mechanisms as a threat to their position, and some initially discouraged their members from joining the Register, but in time most have come to see that this was a valuable addition to user involvement.

The South London and Maudsley NHS Foundation Trust also set up a special section within the Training Department, and although its initial remit was very modest, it has gradually expanded, and now has four user trainers, most of whom have completed the Mental Health First Aid programme. They facilitate a number of Trust events, including taking a key role in some current Trustwide work with

carers. SUITE (Service User in Training Enterprise) has parallels in a number of other organisations, I am for example aware of a similar set up in Hertfordshire, but like many of the developments described above, the value is not just in providing opportunities for service users, but in the inspiring example they provide to other users, and even more importantly in the influence they can bring to bear on staff, some of whom still have quite restricted perspectives on what service users can achieve.

Maudsley International

Maudsley International is a development designed to link the Foundation Trust to countries outside the UK for the purposes of supporting international developments. One aspect of this has been recruiting staff to volunteer overseas in countries such as Sri Lanka. Some staff may be involved in helping to develop mental health services abroad, and others have gone to work within those services. As part of this development it was decided to look at establishing a set of standards which could be developed in partnership with mental health services, pitched at three different levels. There were a number of domains to be developed including in-patient standards, civil rights/legal standards and one for user involvement. The work I had been involved in over some 7 or 8 years provided a natural starting point for this initiative, and it helped me to draw up 3 levels of user involvement for each area within the user involvement domain, in which we would envisage a country's mental health service needing to improve its involvement of service users. This is an on-going piece of work, and presents considerable challenges as it is to be applied to services in countries with very different attitudes to mental illness, and approaches to care. Nevertheless it is possible for example to set an acceptable minimum level for an area such as a person's involvement in their own care, which ranges from being asked by a doctor in a ward round for your views, through to full involvement in a self directed support plan with control over your own budget. The creation of these standards if they reach fruition, could help provide staff in services which are struggling with the tools to improve the basic elements of mental health care, including giving users more involvement in their own care planning, and more say in how services generally are run.

Research

In 2005, I became the social care lead for the South London Hub of the UK Mental Health Research Network, and began thinking about what different roles I could play in the Hub. The research literature on effective user involvement in research was not that prolific. However that year, the Department of Health's publication on the Research Governance Framework, identified user involvement as a key component of good research practice. They suggested relevant service users should be involved wherever possible in the design, conduct, analysis and reporting of research (Department of Health, 2005). An obvious choice for one of my roles was to think about how users could become more involved in the research activities of the Hub. In order to establish a baseline, we set up a conference for users interested in research opportunities. The first conference attracted about 60 users and some other interested professionals and carers. A second conference was equally popular, and we introduced an electronic feedback voting system, in which the results of the voting on a range of research questions were instantly flashed up on screen.

Not that long after the second conference, the central user arm of the Mental Health Research Network, was disbanded. By this time though, we had held a number of meetings with a group of about 20 users interested in becoming involved in research, who had registered their interest at the conference. The outcome of these meetings was that the Hub Administrator and myself developed a menu of opportunities for user involvement in research (see Table 1 below), each level of which identified training that would be made available. This was then agreed with the users.

I was aware that there have been a number of criticisms made and barriers

Table 1

	Tasks Available	Knowledge Needed	Experience / Skills Needed	Training Available
Level One <i>Participatory</i>	Participate in psychology study (for example answering research questionnaire about yourself / your experiences)	None	None	None
	Participate in medicines study (for example trying new medicine and giving bodily samples if required)	None	None	
	Be included on mailing lists to receive research information (for example research findings, new studies underway, service user opportunities in research)	None	None	
	Attend research conferences / events as a delegate	None	None	
	Attend Conferences as additional support for Hub or research teams (for example helping on welcome desk in and handing out badges / packs)	None	Good communication skills and friendly manner	

raised to user involvement in research. One is that users involved in research are not representative of other users, something which I have not found at all. Most of the people in our groups and those who are already involved in research locally, are completely in touch with user agendas. They are the tip of a much bigger iceberg of users interested in research. Some people have suggested users are too close to their own experience of illness and therefore lack objectivity, that they do not understand the complexities of research etc (Wright et al, 2007). There are however many benefits to user involvement in research, as Steve Gillard has shown in his work (Turner and Gillard, 2009). His studies have demonstrated that users who administer questionnaires often elicit a very different and richer, set of responses. Our aim though was to ensure that users had opportunities at every level of user involvement.

Since then we have recruited a user into post, whose role is to interview users interested in research and match them to training and opportunities in research, using the involvement menu. A pleasing outcome of this local development in our Hub is that the involvement menu is to be adopted by other Hubs (Hervey, 2008,b).

Researching the model

The logical extension of all the above developments was that I became very interested in the possibility of setting up a research project to look at User Involvement. In the last nine months this has come to fruition. Together with Diana Rose in the Institute of Psychiatry (Manager of SURE – Service User Research Enterprise), and researchers from Sussex University, North London, Rethink, and Pete Fleischmann at Social Care Institute for Excellence, we have secured a Service Delivery and Organisation programme research grant, to look at the beneficial outcomes of user involvement. This will be a phased study which will include looking initially at the most traditional mode of user involvement, through seven different user groups which will represent the ambit of pressure groups, organisations which provide services for fellow users, groups which campaign, and those which basically provide mutual support to their members. It also includes a group focussed on research activity. They will agree an outcome that they want to achieve and the research will involve tracking how they go about this, and how successful they are, including how well they are able to engage the support of key managers in health and social care. The attitude of key decision makers to user initiatives is one of the key elements running through the study.

Later phases of the project will look at more recent forms of user involvement, including some of those mentioned above, and the last phase will examine the beneficial impact of user involvement in personalisation. This will look at the process of self-directed support, and the use made of their own personal budgets, and once again will scope how this initiative has been received by the said managers/decision

makers. Hopefully this piece of research will provide an evidence base to support the wider implementation of the above holistic framework as a user involvement approach.

Conclusion

It is difficult now to remember the inauspicious beginning to the role I was offered as the Lead on user initiatives - from the relieved handover I received from my immediate predecessor, to the sceptical reception from local user groups to the possibility that anything might change. From my point of view the key to implementing a programme of change was deciding on the initial framework, and getting buy in to that model. Although there have been many bumpy moments along the way, it is this framework which has allowed user involvement to take off in our area of the Trust, and has supported the wider expansion of user involvement in the organisation. The role I took on also included taking the lead for developing carer involvement, and many of the same building blocks (see Figure 1), were used to set up a co-ordinated approach to carer work. Two carers were appointed onto the Mental Health Partnership Board, and they were offered support from a specialist mental health carers' project worker, to ensure that they could access feedback from a number of existing mental health carers groups (four are in place currently). Within the Trust we established a carer's steering group, which had representatives from most of the wards and community teams, who became champions for carers' work in their service area. Most importantly though we introduced a carers training programme and from this we have recruited a number of carers onto the Involvement Register. This has meant we have increasingly had capacity to involve carers in development work (Hervey and Ramsay, 2004).

One of the key elements in this work is the identification of someone with a lead responsibility for co-ordinating user or carer initiatives, and to have a holistic structure around which support systems and opportunities can develop. Whilst this does not need to be someone with a social work background, I would suggest that the values and knowledge base of social work mean that experienced managers from a social care background are uniquely placed to bring together the strengths of a mental health trust, with local authority resources and voluntary sector support systems. Once the framework was in place, any number of user involvement workstreams can be developed. Another local initiative, which presaged some recent work done by Mauger et al (2010), was that following the publication of the Department of Health document on World Class Commissioning (Department of Health, 2010), we undertook a piece of work with our own local commissioners to begin involving users more routinely in the monitoring process for our commissioned services.

Now with the advent of Personalisation, we return to the base of our original pyramid diagram (see Figure 1). The Care Programme Approach, although refreshed

periodically, has begun to look very tired (Department of Health, 1999), and Personalisation, combined with the recovery model, and a much greater emphasis on self-directed support, have provided a rationale for combining personal budget planning with the overall CPA process. The new system of personal social care budgets, with the likely advent of personal health budgets, will require a further culture change for many staff, who will have to take on board the need to shift the balance of power towards their service users. This is a difficult message, especially in health settings where the whole tenor and philosophy of services has often contributed to making people dependent on services.

Many voluntary sector organisations and user led groups are already grappling with self-directed support from a genuine desire to empower their clients, and it will be important as Health budgets come in that the groundwork for enabling and empowering service users has already been done in health settings. The message for the future has to be that service users are for the most part capable of identifying resources to meet their own needs, and they need to be supported to become better informed and more self-reliant. The most recent project that has grown out of my role, is a peer support scheme which we have developed within our Home Treatment Service, and which has already trained 20 users to provide support for fellow patients coming out of the mental health system. With shrinking budgets and a move to community based solutions, it is going to be crucial that statutory services have an organised framework for user involvement, as this preliminary work in shifting attitudes, will enhance the implementation of personalisation. With the shrinking of statutory resources, it is going to be crucial to have robust local user support networks to support clients through the difficult years ahead.

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