

Personalisation in mental health:
Learning from a service user
champions' pilot project



For better
mental health

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Putting us first (September 2008-April 2010) was a Mind project about personalisation in mental health services. It was managed by staff at Norah Fry Research Centre (NFRC) at the University of Bristol, together with support from the Health and Social Care Advisory Service, Southampton Centre for Independent Living and the University of Lancaster. The project took place at a time of change in social care in England, with the introduction of personal budgets and the start of the re-structuring of social services towards self-directed support.

The project involved development and background work, including a literature review and focus groups; a major national conference; the production of a number of publications for practitioners; and support for four champions, with personal experience of mental distress in different parts of England who work promoted personalisation in their own communities.

Between them, the four champions carried out 90 events and reached an estimated 630 individuals over six months. They undertook a variety of work, including one to one meetings, professional training, direct service user contact, mixed events with service users, carers and professionals, and a major regional conference.

Executive summary

This report describes the learning from a Mind pilot project which introduced local service user champions to promote personalisation in mental health services. It draws out the lessons learnt from that project for future practice. The pilot was part of a larger project called *Putting us First*, which found that people with mental health support needs face many barriers to achieving choice and control over their own support services. They are grossly under-represented as Direct Payments users, and the development of Personal Budgets is progressing slowly. Mind would urge that the Department of Health considers action to address the barriers outlined in this report.

The success of the service user champions' pilot project depended on:

- Careful selection of individuals who had the right experience and skills
- Support and training delivered by experienced and knowledgeable people
- Resources given to champions, which were tailored to need
- Creating a network of support for the champions, from a central team and peer support
- Leadership by people who had personal experience of mental health support needs.

There was no single 'right' approach for all the champions to take. Their activities varied, but all of the champions needed to be flexible enough to take the opportunities that arose, and to be able to communicate well with a very wide range of people at many different levels.

Breaking into existing local networks was hard for service users who were not already connected with those networks. It takes time and persistence to find out 'who's who' and champions are likely to need support with this.

There is a need to establish clarity from the outset regarding the role of champions, in relation to professionals, groups and individual service users. It may be useful for champions to link up with local advocacy services in case they can offer individual support.

When working with professionals, champions may be most effective at changing attitudes; when working with carers and service users they can play an important role in increasing knowledge.

Increasing knowledge and awareness works well when the focus is initially on the concept of personalisation, not the process of offering and arranging a Personal Budget.

Co-production can be a very successful way of promoting change. An effective approach to promoting personalisation is to enable professionals, service users and carers to make joint progress, and to learn together and communicate with each other.

It is essential to recruit and support champions who can tread the fine line between being a 'service user' and being a professional. A range of skills are necessary for this to be successful, including commitment, knowledge, information, confidence and persistence.

The most effective service user champions are those who already have a good network of contacts and a strong reputation locally, and who have already gained the trust of others.

Key recommendations

- Using service user champions is both a good idea in principle and an effective way of delivering services and messages. As Putting Us First showed, there are individuals with suitable experience and expertise out there, ready and waiting. More work of a similar nature should be funded and supported.
- The work of a service user champion can involve many different levels of training, networking and contact with professionals and service users. Some of the most successful examples of change in the current project involved conversations between professionals, service users and carers. That provided the greatest impetus towards changes of attitude.
- Support for the work of champions is essential. This project has shown that the best support is that which is delivered by other mental health service users who can be role models for the champions.
- When champions are recruited, they need to receive well-planned and person-centred training and resources. This project was on the whole able to achieve that.
- Projects to support champions need to plan carefully for ways of remunerating the champions effectively. That aspect should be built in from the start.
- Adequate time needs to be given to champions to help them achieve their goals, including fundamentally changing the way people with mental health support needs are perceived by service providers and managers.
- Success breeds success, and local gains in personalisation can be spread to neighbouring areas and networked through local contacts. Service user champions should be a major part of that endeavour.
- At local level, champions should be recruited more widely, to shift prevailing cultures, enable attitude change and assist in the spread of knowledge about personalisation.
- Conducting champions' work within the context of a major national organisation like Mind gives credibility to the work locally and allows messages to reach a wider audience. This should be considered in future projects, particularly as power and decision making in mental health continues to be devolved.
- Mind recommends this approach, both at national and local level, as it enables policy makers and strategic managers to engage closely with the perspectives of mental health service users in the shift towards personalisation and supports a commitment to service user involvement.

1. Introduction and background

Summary

- People who have used Personal Budgets, including Direct Payments, and who have direct experience of mental distress, are in the best position to support others. This was a project led by people with mental health support needs.
- The difficulty of separating health and social care needs makes for difficulties in implementing Personal Budgets in mental health.
- Some professionals lack trust in the ability of some service users to design their own support.
- The re-design of social care for personalisation needs to take into account the Care Programme Approach (CPA) which is significantly different from care management in social services.
- The barrier to success appeared to be in the attitudes, knowledge and skills of frontline professionals, including care co-ordinators in Community Mental Health teams.

This report considers the final phase of a Mind project called *Putting us first* which was delivered between October 2008 and March 2010. The project aimed to increase the uptake of Personal Budgets, including Direct Payments, by people who use mental health services. In order to achieve this goal, *Putting us first* carried out the following activities:

- A literature review¹, to increase knowledge and understanding of the current state of play in personalisation and mental health, including the barriers which operate for people with mental health support needs
- Four focus groups of mental health service users, in order to find out what service users might want, if they had the choice and control of a Personal Budget²
- A major national conference to bring together key players, senior politicians, practitioners and service users. This was held in July 2009
- A resource for practitioners was produced, which provided answers to some of the common concerns about personalisation in mental health³

Putting us first was designed from the outset to be led by the voices and experience of people with experience of mental distress. Project leadership by people with mental health support needs was closely allied with a rights-based approach to personalisation and mental health, recognising that people with mental health support needs were grossly under-represented within the development of Personal

¹ Heslop & Williams (2009b) Personalisation in mental health: Views of personalisation, from people who use mental health services.

² Heslop & Williams (2009c) Personalisation in mental health: A review of the evidence.

³ Heslop & Williams (2009a) Personalisation in mental health: A guide for care coordinators

Budgets in general, and as Direct Payment users. The first stages of *Putting us first* underlined the barriers to personalisation being experienced within mental health services. In addition to general problems in adopting a personalised approach that is applicable to all client groups (such as changing commissioning practices), there are specific issues in the field of mental health. These include:

- Difficulty of separating out health from social care needs
- Lack of trust among many professionals about the insight and responsibility of some service users
- Fluctuating nature of mental health distress for many people
- Difference between the Care Programme Approach (CPA) in mental health and the care coordination approach in social services more generally

A key theme that arose from the early work in this project was the need to fill the knowledge gap amongst care co-ordinators and other frontline staff. The resource for care co-ordinators written by the project team was disseminated widely as a tool to address that gap. However, all the early phases of the project were designed to lead to the final stage of the work, the champions' pilot project.

Four service user champions were recruited to promote personalisation in their own communities. The main purpose of the pilot was to learn lessons about how to embed a similar approach across the country. An evaluation was therefore planned to run alongside the pilot. For an account of the methodology used for the evaluation, see Appendix A.

This report offers an overview of what was accomplished in the pilot project, both in terms of how it was set up and prepared, and also in terms of what the champions achieved. It also offers an evaluation of the outcomes. Finally, we discuss the role of service user champion as it evolved in the *Putting us first* project, and the lessons that were learnt about how to recruit and support service user champions to promote personalisation.

2. Setting up the service user champions' pilot project

Summary

The success of the pilot project depended on:

- Careful selection of individuals who had the right experience and skills to match the role of being a service user champion.
- Support and training that was delivered by experienced and knowledgeable people.
- Resources given to champions, which had been developed in earlier stages of the project and were tailored to need.
- Creating a network of support for the champions, that was provided by the central team and via peer support.
- The ethos of the project itself, in that it was led by people who had personal experience of mental health support needs.

The four champions were recruited through a fair selection process, led by Mind, which included advertising through Mind's networks, short-listing against clear criteria, and an interview. Four of the people who submitted applications met the basic criteria for the job; they were all interviewed and subsequently recruited as champions. The criteria proved to be vital for the role, and included that each champion would:

- have experienced mental distress,
- have used secondary mental health services and Direct Payments or Individual Budgets to support their own recovery / management of their mental health needs,
- be passionate about empowering other service users,
- have experience of delivering training,
- have a willingness to learn,
- have a willingness to travel (nationally for training and local/regionally for work),
- be able to work under own initiative, i.e. self managing in their work,
- accept supervision and support as offered,
- keep records of their progress and outcomes.

Desirable criteria were that each champion would:

- have a general awareness of personalisation,
- be linked to networks of mental health service user/survivors in their area,
- be linked to other users of Direct Payments or Individual Budgets,
- have a willingness to work flexibly to meet the requirements of the project.

The full role description is in Appendix 2.

These are quite stringent criteria. However, as this report shows, the tasks associated with this role were demanding, and it proved wise to exercise care in selecting individuals who would be able to manage the role. The appointed champions all had prior experience in very similar roles, were mental health service users themselves, and had an understanding of personalisation. They also, in various ways, already had links in their communities. These included:

- Membership and leadership of local campaigning groups.
- Existing experience of working in partnership with professionals and local policy-makers.
- Links and networks with other service users locally.

The champions were recruited in September 2009 and their period of work was six months (October 2009- March 2010). This gave them a very short time to settle into their roles, develop new connections and deliver any events or training. The prior experience they brought to the role was therefore essential. Given the short timescale, the achievements of the champions were remarkable (as will be explored further below). Their contribution to the *Putting us first* project was extremely important, and it is hoped that this report will help others to realise the potential of service user leadership as we see personalisation in mental health increased.

Champions were offered support which was provided by three people, all of whom identified as mental health service users themselves. All three had professional roles in promoting, researching and writing about personalisation and mental health, and they thus acted as role models for the champions.

Formal aspects of the support included:

- The recruitment process itself, in which questions and dialogue with the team could start
- An initial training day
- The provision of materials and resources: copies of the *Putting us first* resources and electronic copies of presentations and other materials about personalisation and mental health

When asked about these aspects of the project in the first three months, all the champions reported positive experiences, in particular:

- The recruitment phase was informal, friendly and appropriate.
- The training day was useful.
- The direct support given was useful and accessible. The champions liked the choice of telephone or email contact, with occasional visits. They all felt it was valuable to have information and guidance available, as and when they needed it.

Because of the way in which the project was set up, all the champions not only met the *Putting us first* team at the beginning of the pilot project, but they also met each other and agreed to stay in contact. This aspect of the pilot proved to be vital in providing peer support, and enabled the champions to:

- stay in email contact with each other
- share worries as well as successes
- discuss particular issues
- share specific advice and information.

3. The activities carried out by the service user champions

Summary

- All the service user champions provided training, information and advice about personalisation to people locally, but each champion took a slightly different approach to the task. There was no one 'right' approach.
- Between them, the four champions carried out 90 events, and reached an estimated 630 professionals, carers and service users over six months. They undertook a variety of work, from one-to-one meetings to a major regional conference.
- The champions needed to be able to communicate well with a very wide range of people at many different levels.
- Getting into existing local networks could be hard for service user champions who are not already connected with those networks. It takes time and persistence to find out 'who's who' and champions are likely to need support with this.
- Service user champions can act as catalysts to promote change. This happened in the pilot project, both through smaller and larger events – including a major regional conference.
- There is a need to establish clarity from the outset regarding the role of service user champions, in relation to professionals, groups and individual service users.
- It may be useful for champions to link up with local advocacy services in case there is a need for individual support.

The champions all had the same information and background guidance for their tasks, but they were all in different situations and local contexts. Each of them was supported to develop their own unique approach to the role, and in practice, this resulted in four different strategies to promoting personalisation in the mental health field. Table 1 shows the strategies adopted by each of the champions.

Table 1: The strategies adopted by each of the champions

Champion 1	To network and enable key players locally to talk to each other.
Champion 2	To bring together key players for a major event which would provide a stimulus for future work.
Champion 3	To reach service users directly, and enable them to see that Personal Budgets, including Direct Payments, could benefit them.
Champion 4	To present the ideas about personalisation to a wider audience, including the general public.

Each of the champions benefited from an existing local profile, and networking was one of the key initial activities, carried out in various ways and at different events.

One of the champions in particular planned his activities very explicitly according to knowledge of existing local networks. Having mapped these out from the start of the project, he was then able to tick off people he had accessed and made progress with. He reported:

“The initial mapping was very valuable. I needed to know who was doing what. I knew Susan⁴ already, but I went from her, and spread out and got knowledge about other people. Wheedling my way in.”

This champion took the existing progress made within his local area into a new, neighbouring local authority, where he took part in professional forums, presented at practitioner workshops, and led sessions which involved professionals, service users and carers. Essentially, he was able to translate existing lessons from one local authority directly to the key players in a neighbouring authority, including the personalisation leads and team managers.

Another of the champions used his existing networks and local knowledge to discuss and plan a specific event, which became a very successful, local area conference. It was through his enthusiasm that local authority and other professionals started to support and lend their time to make this event happen. The champion in this case had a direct role as a catalyst, and helped in what he later described as ‘co-production’. The actual challenges he faced included:

- Securing the funding.
- Bringing together key players and speakers.
- Ensuring that the conference was delivered in a co-productive way.

⁴ All names have been changed to protect anonymity.

Over 100 people attended the local conference, representing a range of provider organisations, voluntary bodies, carers, service users and senior managers in mental health and in the provision of support with Direct Payments. The conference featured national-level speakers, presenting the messages about personalisation, and incorporated a series of workshops at which people could find out more about specific aspects, including capacity issues, carers' needs and managing risk. Fuller details about the outcomes related to the conference are given in the following section – Outcomes of the pilot project.

A third champion chose to work chiefly with individuals, and was encouraging other mental health service users to use a Personal Budget to join in a local football team. The question arose as to whether the champions should be working directly with service users, or using their influence more widely to engage with professionals. In fact, all the champions in reality engaged with a range of individuals, and sometimes were able to speak with mixed audiences. This was felt to be particularly valuable, since they were able to ensure better communication between local service users and professionals. One champion commented:

“It works well to have a mixed group, because you can bring skills out of people. One person said, “how do you know the difference between my health and social care needs? Because health needs aren't covered by the Direct Payments”. I looked to the Trust exec, and he said “There are pilots going on, we're looking at that”. And then the officer came in with his bit about looking at quality of life, and outcomes and things. It was like a dialogue going on, excellent.” The fourth champion set out to run events in mainstream, community environments, in order to spread the messages about mental health and personalisation more widely. She was also successful in running at least three meetings in public settings. However, due to health problems, she had to withdraw at an early stage from the project.

The four different approaches to the task of being a champion resulted in a variety of different outcomes, which will be explored in the next section of this report. The diversity of approaches was influenced by the local context, as well as the particular position, previous knowledge and experience of the individual champions. The pilot did show that a variety of events can all lead to similar outcomes and goals, namely:

- Increased awareness amongst professionals regarding personalisation and Personal Budgets for mental health service users.
- A stimulus to service users and carers themselves, to encourage greater enthusiasm for Personal Budgets. Essentially, this entailed showing people what was possible, and helping them to get a new vision of what their own lives could be like.
- Better communication channels between existing professionals in the area, so that progress could be made towards making Personal Budgets a reality for mental health service users.

Table 2 presents a summary of the activities of the service user champions. It details the events undertaken and the people reached by the work of all four of the service user champions.

Table 2: The activities of the service user champions

Type of event	Number of events <i>over all 4 champions</i>	Approximate number of people reached
Attending service user meetings or forums	13	117
Running a conference	1	109
Presentations to professionals	11	102
Contributing to workshops with professionals	8	80
Presentations to mixed groups of professionals and service users	4	69
Taking part in workshops or meetings with professionals	4	40
Presentations to service user groups	6	36
Planning events or conferences	10	24
Presentations to carers or others	3	21
1-1 meetings with professionals	18	18
1-1 meetings with service users	11	11
Attending conferences	1	3
Total	90	630

4. Outcomes of the pilot project

Summary

- The pilot project was successful in increasing awareness of personalisation amongst professionals. Awareness-raising may need to come first, before the learning of specific knowledge and skills.
- When working with professionals, champions may be most effective at changing attitudes, but when working with carers and service users they can play an important role in increasing knowledge.
- Increasing knowledge and awareness works well when the focus is initially on the concept, not the process. Mixed audiences can work well here, and the four champions were able to promote communication between service users and professionals about Personal Budgets.
- Co-production can be a very successful way of promoting change. The regional conference initiated by one of the champions attracted over 100 participants. The organisation and delivery of the conference were taken on by local professionals.
- The champions promoted a fresh vision of personalisation and a holistic way of looking at individual outcomes.
- The champions were able to encourage other service users to use Personal Budgets, and provided some peer support.

Given the short timescale of the pilot project, it was not expected that a tangible increase in uptake of Personal Budgets would be identified. Instead, the task for all four champions was primarily to sow the seeds of change, and to start influencing the attitudes and knowledge of professionals. From those changes, the eventual outcome of increasing the number of service users in receipt of a Personal Budgets would be a longer-term achievement.

The champions clearly did achieve a number of outcomes. These included:

- Finding out about the need for information and guidance about personalisation
- Changing the attitudes of professionals towards personalisation
- Increasing awareness of personalisation amongst mental health professionals
- Promoting a holistic approach to personalisation
- Providing challenges to professionals
- Supporting other service users
- Informing carers
- Networking through a regional conference.

Finding out about the need for information and guidance about personalisation in mental health services

The champions' activities laid down an indicator of the need for more information and guidance about personalisation in mental health. It is clear that the first steps towards change are still needed in some areas, but that a slow groundswell of change can be started by the work of service user champions. For instance, one of the champions reported visiting a community mental health team. He had anticipated fifteen minutes of questions, but was in fact kept there for two hours. The team he spoke with had a very limited knowledge of Direct Payments, let alone Personal Budgets. Another professional commented that the champion was *“dragging it to our attention”*.

Changing the attitudes of professionals towards personalisation

All four champions were able to help professionals see personalisation in a new light. They made inroads to changing attitudes to more positive views of personalisation in mental health. In general, the champions felt they had most value at the level of attitude change. One champion reflected:

“The ones that have worked for me have been where I’m selling the idea of personalisation rather than the process. You can learn a process any time, but you can’t learn the idea of the benefits that it has for people every day. That’s where it’s really helped people to understand how Direct Payments or a Personal Budget can help people – not only to get out and enjoy life again, but play active roles in society. It’s the hearts and minds stuff, it’s trying to inspire people.”

In particular, service user champions helped professionals to see the value of personalisation, whereas it had previously seemed like a threat, something imposed ‘from above’. One professional, who had attended an event led by one of the champions, said that some mental health professionals were fearful about personalisation and felt that Personal Budgets might present a threat to their own jobs. She commented

“We can allay those fears through this project.”

The champions necessarily had to spend a large proportion of their time on meetings, planning, contacting and networking. However, the process of networking and planning was valuable in itself, and some of the attitude changes could be attributed to quite casual and informal meetings, where champions were explaining their role to local professionals.

Increasing awareness of personalisation amongst mental health professionals

Direct contact with professionals was the central feature of the champions' activities, and independent evidence from professionals who had attended their events indicated how important these were to generate discussion, interest and awareness about personalisation. One personalisation lead commented:

“[The event] was very well received by all in attendance and generated considerable discussion and questions which (the champion) answered well. I am also aware that he has presented the same package to adult social services audience and this was mentioned by one of the commissioners at a recent local project management board on personalisation that I attend. His input had been greatly appreciated by that audience as well.”

The general effect of the training events for professionals was to increase awareness as well as establish a more positive attitude towards personalisation in mental health. Feedback to the champions following training events was universally positive. Staff who had contact with the champions felt that they had:

- learnt more about personalisation,
- been able to voice their concerns and problems in a safe environment,
- had access to information and useful resources to enable them to pass on messages and training to other staff.

Through encouraging a positive attitude and increasing knowledge about personalisation, there was some early evidence from the project that the offers of Direct Payments to mental health service users were increasing. The following comment from one of the champions was confirmed by the local Direct Payments officer. The champion reported:

“It's the staff I've been pushing. And they have gone out, and got people onto Direct Payments. I know it's happening, I can see the figures go up from 15 to 28 to 32. It's brilliant.”

Promoting a holistic approach to personalisation

Evidence from evaluating the work of the champions suggests that service user champions can lead the way in supporting an attitude shift away from impairment specific silo-working. One professional reported that one of the champions was involved in producing a non-mental health specific leaflet about personalisation; another of the champions was aware that the conference he facilitated attracted interest from professionals beyond the field of mental health. This was substantiated by two of the evaluation feedback comments, which referenced older people and people with learning disabilities. The champion commented:

“A Personal Budget is about the individual, and we need to break down the barriers between different impairments, different teams. This would save money as well if you're working jointly.”

Providing challenges to professionals

One of the key achievements of service user champions was to challenge some of the barriers that professionals raised, when discussing personalisation. It seemed that they were in a good position to provide this challenge in a non-threatening and positive way.

For instance, mental health professionals sometimes felt that Personal Budgets could not happen because of a lack of resources: *“There is no new money”*. Such an attitude can prevent the development of a more personalised approach for service users. When faced with such a comment, one champion was able to challenge the professional with robust information about the rights of mental health service users, and figures for Personal Budget users in the locality. The champion recounted:

“She said ‘We are aspirational at the moment’. And I said ‘no you’re not – this is government policy’.”

Supporting other service users

There was some evidence from this short project that taking a direct approach with other service users could be successful. This was particularly so when the champions could keep in touch and give advice and support to particular service users.

One of the champions in particular felt that he could be most effective by focusing directly on service users, so that they would realise for themselves the benefit of Personal Budgets. In that way, service users' own demands could create a groundswell for change. Another of the champions also felt that change at individual level was important. He considered:

“For every person that understands and achieves Direct Payments or a Personal Budget out of our work, we know that we have changed that person’s life for the better.”

One of the professionals who gave feedback for the evaluation also felt that a service user champion could have an important effect on persuading other service users to consider Personal Budgets in their own lives. Yet organising events to attract service users proved quite difficult on occasions. Additional publicity was needed to back up events for service users. The evaluator attended one planned event, which apparently had been advertised locally, but where no service users attended. Where it did happen, direct contact between champions and other service users enabled a dialogue to start: it is that dialogue which will enable progress to continue in localities. One champion explained:

“One of the things I was doing at the mental health group is to get people to know what questions to ask. Not necessarily to ask them there and then, but the next time they see their care coordinator – to say ‘I want to do a painting course’ or something like that. And ‘how are you going to do that then?’ ‘I could have Direct Payments’, and then ‘what are Direct Payments?’ ‘Well I went to this talk the other night....’ It’s giving them the words to go with.”

In one area, a service user attended an event run by one of the champions, and told others about it. One of his friends was enthusiastic to apply for a Personal Budget for his own needs. He wanted to get away for a holiday, and to apply for £9000. This was considered very unrealistic by the local mental health team, but the champion was able to maintain contact, and advise the service user to express his needs in a different way: I'd suggest they ask annually, and get their outcomes going each year, so they get the first year's payment, and if they get their solid outcomes, then they [decision-makers] can't say 'no'.

Informing carers

The champions also had a role informing family members and carers of people with mental health support needs. As can be seen in Table 2, some of the training events run by champions included carers, or were specifically for carers.

What carers needed to know was how Personal Budgets could relate to them, as well as the relative they cared for. Again, it proved important for champions to be well-informed about the policy and law relating to carers. The issues raised by carers included:

- Worries about Personal Budgets, and their confusion with social security benefits.
- The role of family carers in employing personal assistants
- How to get into the system in the first place.

The champions' contact with carers was important, because they were able to demonstrate that Personal Budgets could support them in their own lives. However, as with service users, a successful strategy was simply to bring carers together with professionals, so that the questions could be aired, and the dialogue started. As one champion said:

‘You've got to ask the questions – and that's what we're doing here now.’

Networking through a regional conference

A regional conference was initiated by one of the four champions. Over 100 people attended the conference, including personalisation leads, care co-ordinators, service providers, voluntary sector professionals, service users and carers. As the champion himself commented, this was real 'co-production':

“I've had brilliant back-up for this conference – no-one can do it all on their own, it's about co-production and getting willing parties to work together. It's not about selling just the 'Putting us first' project. It's about selling the end product.”

The event consisted of plenary presentations given by national speakers, with a choice of workshops led by local organisations, personalisation leads or other key staff. The local venue had good catering facilities and had space for participants to set up stalls and share their activities and information. This proved to be an important part of the day, and provided a relaxed and informal 'shop front' atmosphere. The

champion noted that setting up a successful conference involves getting all these aspects right.

At the end of the day, an interactive audience response system (Qwizdom) was used to get feedback on the day, and 72 people took part. Of those, 44 people said their knowledge of personalisation had increased on the day because of the conference. Fuller details of the evaluation are given in Appendix C.

Participants were also asked by the evaluator about their views and experience of the conference. Sixteen interviews were conducted with seven professionals, four carers and five service users. Each participant was asked about why they had come to the event, and was asked to rate their knowledge about personalisation and Personal Budgets both before and after the event on a 1-5 scale. The results of the self-evaluation are given in Table 3.

Table 3: Evaluation of own knowledge of personalisation by participants at the regional conference

	Professionals (7)	Carers (4)	Service users (5)
Self-rating before the event	3.5	1.75	1.2
Self-rating after the event	4.5	3	2.4
Sum effect of the conference	1	1.25	1.2

Five-point scale for evaluation of knowledge about personalisation
 5: very knowledgeable, 4: know the main things, but hazy about some issues, 3: know a bit, 2: don't understand much, 1: never heard of it before

One of the social care managers interviewed noted that the move towards Personal Budgets represents a 'cultural shift'. To make this shift, they said:

"It'll take examples of people using Personal Budgets and the ways in which organisations have changed."

The two social workers interviewed felt the conference raised questions rather than giving them neat answers. They both had experience of offering Direct Payments to service users, and were keen to learn more about personalisation. They were also planning to feed back to their whole team after the conference.

The carers who were interviewed belonged to a carers' forum. They had a very low level of knowledge about Personal Budgets before the event, and gained a lot just by hearing about the possibilities for their family members and friends. As one of the carers commented:

"I think I've learnt a bit – that 'it's not just about services'"

The carers were well aware that Personal Budgets were about choice and control for service users, but felt that it was important for carers also to have knowledge and information about how Personal Budgets were going to work.

Four of the five service users who were interviewed belonged to a group from a particular service organisation. The level of knowledge of all service users before the conference was low, but they were inspired by the talks and particularly by taking part in workshops. One of the service users had some interesting comments to make about his own plans for the future. He had never heard of Personal Budgets before the conference, but commented:

“It just sounds as though it’s a good way of deciding what you want – making your own decisions.”

He was not sure about employing a personal assistant, as he felt that could be risky. However, he said that he had an idea about applying for a Personal Budget to set up a gardening project. As a trained horticulturalist who teaches gardening, he felt that he would like to set up a community garden for people with mental health needs. He left the conference intending to talk to his psychiatrist about that plan.

In general, the outcomes from the conference were extremely positive, as was indicated by the electronic evaluation used at the end of the event (see Table 4). One of the professionals who helped organise the conference said:

“I enjoy the whole engagement process and helping others to get the right information so it was a pleasure to support you. I look forward to more opportunities.”

The champion instrumental to the conference commented:

“This (conference) is something we can build on now, and really have that impetus. Through today, we’ve got a real willingness from the senior staff to actually work with me, as a champion.”

5. The role of the service user champion

Summary

- Service user champions had to negotiate their way between being a service user and being a professional. Identity as a service user was essential to the role and important to maintain.
- The skills required in undertaking the role of champion involved considerable knowledge and professionalism.
- Local networks and previous experience with service providers, service users or local organisations is invaluable to champions. The most effective service user champions are those who already have a good reputation locally and who have already gained the trust of others.

From the experience of the *Putting us first* pilot project, it was concluded that the role of being a service user champion was a sensitive one that required negotiating a balance between being a service user and being a professional.

The champions needed to become experts about personalisation. Following their training day, champions were given resources which they could use or adapt for training. This included *Putting us first* resources and a standardised presentation about personalisation. Some of the champions successfully adapted these tools to suit their own needs. One of the presentations given by a champion was video recorded, and it clearly shows how the information was professionally presented, and questions answered. He was able to counter and challenge misleading statements made by local professionals, demonstrated knowledge about the rights of people with mental health needs to access Personal Budgets, and offered information about the numbers of people in receipt of Direct Payments or using a Personal Budget. The presentation was delivered in a diplomatic way, and the champion carried out his work in a very professional and sensitive way.

Given that high level of skill was required, were these champions simply 'professionals'? On the contrary, the aim of recruiting service user champions was to ensure that the views and experiences of service users themselves were at the forefront of personalisation and the development of good practice. The concept of 'being a champion' implies a type of identification with a constituency or a movement of people, who share a common experience. All the champions had a fine line to tread between being a 'service user' and being a 'champion for the issues of personalisation in mental health'. One of the champions spoke about that tension very eloquently:

"I think you have to draw a line between a service user and a service professional. And (we) want to sit in the middle, one foot in each camp. Because you need professionalisation in order to be able to talk to people, but you also need that service user touch, to say 'I'm where you are'. And I think you've got to straddle that. And it's difficult. If you straddle it too far to one side, you become a professional and you lose the touch. People then don't listen to

you. If you keep turning up with the same social services staff, then you become staff in their eyes.”

Three of the four champions brought to the job particular experience and a background of service user involvement work in their own communities. One of the four already had a number of offers to work with professionals, both in his local area and in neighbouring areas. In effect, as he said, he was able to ‘bolt on’ the role expected by the *Putting us first* project, and to build on his own contacts. This was what gave him an edge over others who may have tried to move personalisation forward in that area. This local knowledge by and of service users and professionals was important to another of the champions too. Both felt that the *Putting us first* project gave them extra contacts and status beyond being a service user that they used to extend their existing involvement activities and profile.

It was clear that some of the tasks undertaken would not have had the same effect if they had been delivered by people who were not service users themselves. The main supporter for the champions, who herself speaks up for other service users, summarised the value of this role in this way:

“I think sometimes practitioners are very sceptical, and are bombarded with conflicting information...they need to taste success. And a service user champion can show them how you manage, and show them that it’s possible. And use opportunities and power. Being a champion is about saying ‘I’ve done it, and I’m still there’.”

6. Lessons learned from the service user champions' pilot project

Summary

- The champions were enthusiastic and motivated: this led to some difficulties with them pacing their work. Service user champions need good support, preferably delivered by experienced service users.
- It is not necessary for the support to be based locally. In fact, the champions valued the autonomy they were given, by the fact that the project support was 'at a distance'.
- The six-month timescale was a pressure on the champions. The role of a service user champion takes time. If things are rushed, then that can impact negatively on the pace of activities undertaken by the champions, and consequently on their health.
- Any financial reward offered to service user champions needs to be carefully worked out and discussed before the project.
- Peer support provided to the champions worked well.
- A project based in a national organisation, such as Mind, can give an added status and impetus to the local role of a service user champion.

Putting Us First provided the framework and support for the four service user champions who took part in the pilot project. A number of lessons were learnt through the course of the project about what worked well, and what was not so successful, in supporting service user champions. Key issues included:

- The personal outcomes for the champions
- The short time-scale of the project
- Payments to champions
- Support provided to the champions

The personal outcomes for the champions

During the first three months of the project, the general feeling about the work amongst the champions was very positive. One of the main comments, repeated by more than one of the group, was that the project gave them 'status', and they felt that they were recognised in their communities as delegates of Mind. One champion explained:

"The project gives me the ability to get into conferences, a bit of status. Once I was given the boost, what I was doing casually on a one-day a week basis, helping out my mates, it's now I'm doing that on a full-time basis."

All four of the champions set about their tasks with great enthusiasm, and generally felt that the project gave them the chance to develop what *they* felt was important. This aspect is important, since personalisation itself is about individuals having autonomy to control the direction of their lives. The project to some extent mirrored the principles of personalisation. One of the champions reflected:

“The luxury I have on this project is that I chose my own direction.”

All four of the champions stepped into roles that brought status, autonomy and control, and this clearly had an effect on their own levels of confidence. One of the group, towards the start of the project, said that his confidence had ‘gone through the roof’, and some of them enjoyed feeling that they were seen by professionals locally in a new light. This was partly because of their increased ‘national’ status, but also because they had the opportunity to make common cause with other disabled people. In effect, their identity went beyond that of being a mental health service user. Now they were champions for the personalisation cause. One member of the group expressed the personal effect of all this on their own life:

“Doing this project has put a spring into my step.”

The short timescale of the project

The champions took on a large amount of work, and some felt under pressure to deliver positive outcomes in just six months. Yet rushing things through was not always realistic or helpful. One professional commented that the champion’s work needed to be gradual and to work slowly at changing attitudes. They said:

“(The champion)’s been very good. I don’t think we’ve really had the chance to see the effects of it yet. I think with Direct Payments, it’s a drip-drip, it builds up.”

The pace of work proved to be a difficulty for some of the champions. At times some felt the pace of the work was enjoyable. One explained:

“When I take on all this work, people tell me to take it easy. But I enjoy it, because it stimulates my mind.”

However, three of the four champions had to take periods of time out of the project due to health problems over the second half of the pilot. One did not return to her role as service user champion. Perhaps surprisingly, the champions did not consider this to be a negative outcome of being a service user champion: in a sense it was seen as ‘par for the course’, and the positive results of the project were a stimulus and boost to all of the champions at the end of the six months.

The positive attitude at the end of the project was a tribute to the hard work that champions themselves had put in, and also the success of their efforts. Several of them expressed the wish to carry on with similar local work after the end of the project. One said:

“I’m not finished even now with the project – I’ve got a meeting in about a fortnight to see what we may do with the rest of the money – I would like to do

another conference later in the year, more about Personal Budgets and personal planning.”

Despite the short time period of the project, and the pace of work that the champions worked at, the net effect on champions themselves seemed to be positive. One of the champions explained:

“There is no alternative than to have high goals. It’s always going to be important to set high goals.”

Payments to champions

Another major issue, during the champions’ phase of *Putting Us First*, concerned payment. From the outset, the roles of champions had been advertised as part-time, paid posts. However, the issue of earnings became a major stumbling block, when some of the champions realised they could not accept payment from the project without it affecting their social security benefits entitlements. In effect, the role was not enough of a job for them to come off benefits (because it was short-term and only a few hours a week), but too much of a job to be permissible under benefits rules. All of the champions and project leads felt that the champions’ roles consisted of skilled, professional work and that they should have been appropriately remunerated.

The champions found themselves in different positions regarding their ability to accept a fee for their contribution, and most chose to take on the role of champion in a volunteer capacity. This created a risk to the success of the project, although it is to the credit of all the champions that none of them allowed this to influence their positive attitude to continuing the work.

Support provided to champions

As outlined earlier in this report, the four champions were not alone. They were recruited to a team project, which had already produced a range of resources for them to use. Additionally, there was a planned system for them to receive support in their roles, delivered by experienced team members, who identified as mental health service users/survivors. In general, the framework of the project and the support offered were perceived as very positive by all the champions.

Both the champions and supporters felt that it was better to have someone providing support who was *not* involved in the community. That meant that she or he could understand the issues with greater objectivity, and did not risk taking over the champion’s role. It was essential, of course, to be responsive to champions’ requests, and to have the right information and advice to give them. In these respects, the *Putting Us First* project was clearly successful, as one of the champions reported at the end of the project:

“What has been the best help for me is knowing the support is there. If I get a situation where I don’t know what to do, I’m only a phone call or an email away. And the response is good, positive, with the right information. I don’t know it all, but I know a friend who does. That’s the back-up that we need.”

Champions felt they were not alone. They reported how important it was that the support from the project was given by someone who understands and has also experienced mental health issues. This was re-iterated by the main supporter herself:

“My own role as a mental health service user was essential, it gave leadership and inspiration. I have done lots of similar work, and lots of involvement – and they ask me about other aspects of my work too. It’s encouraging to them, and they see me on the same level, and aren’t frightened of me.”

7. Conclusions

- Using service user champions is both a good idea in principle and an effective way of delivering services and messages, and as Putting Us First showed, there are individuals with suitable experience and expertise out there, ready and waiting. More work of a similar nature should be funded and supported.
- The work of a service user champion can involve many different levels of training, networking and contact with professionals and service users. Some of the most successful examples of change in the current project involved conversations between professionals, service users and carers. That provided the greatest impetus towards changes of attitude.
- Support for the work of champions is essential. This project has shown that the best support is that which is delivered by other mental health service users who can be role models for the champions.
- When service user champions are recruited, they need to receive well-planned and person-centred training and resources. This project was on the whole able to achieve that.
- Projects to support service user champions need to plan carefully for ways of remunerating the champions effectively. That aspect should be built in from the start.
- Adequate time needs to be given to champions to help them achieve their goals, including fundamentally changing the way people with mental health support needs are perceived by service providers and managers.
- Success breeds success, and local gains in personalisation can be spread to neighbouring areas and networked through local contacts. Service user champions should be a major part of that endeavour.
- At local level, service user champions should be recruited more widely, to shift prevailing cultures, enable attitude change and assist in the spread of knowledge about personalisation.
- Conducting champions' work within the context of a major national organisation like Mind gives credibility to the work locally and allows messages to reach a wider audience. This should be considered in future projects, particularly as power and decision making in mental health continues to be devolved.
- Mind recommends this approach, both at national and local level, as it enables policy makers and strategic managers to engage closely with the perspectives of mental health service users in the shift towards personalisation and supports a commitment to service user involvement.

Appendix A - Methodology for evaluation

The evaluation of the champions' phase of *Putting us first* was carried out alongside the actual work of the four champions. It was not planned as a 'separate' activity, but was able to offer an objective viewpoint on the work, as it was led by Val Williams, who was not connected at that point with managing or supporting the project.

The goals of the evaluation were:

1. To assess progress that has been made, including identification of factors which have assisted or hindered progress in personalisation and access to Personal Budgets, including:
 - Analysis of the range of activities undertaken by champions
 - Analysis of approaches which have worked well and not so well
 - Suggestions as to which components of the champions work could appropriately be applied more broadly
 - Suggestions for additional strategies which might be used to provide sustainable and culturally appropriate personalised mental health services
2. To assess the short-term outcomes of the champions phase of the project, wherever possible, particularly in relation to:
 - Improving access to Personal Budgets for mental health service users
 - Improving mental health outcomes for people via a more personalised approach
 - Enhancing the appropriateness and effectiveness of mainstream and specific mental health care
 - The views of mental health professionals about personalisation
3. An assessment of the personal and professional support provided to the champions, including:
 - Analysis of the support provided and that considered to be most effective
 - Communication between the champions and champion associates
 - Lessons learned from the experience of supporting mental health service users in the role of champions
4. To provide recommendations on how and when to evaluate the medium and long-term outcomes of the project, to ensure that this essential data and learning are not lost.

Criteria for evaluation

One of the key principles of the champions' phase of the work was that each champion should have a degree of autonomy in shaping their own work. Therefore, the criteria for success were bound to be slightly different for each person, and linked closely with what they set out to achieve. This was therefore an open-ended evaluation which aimed to discover and explore the difference made by the work of the four champions, in some very different local circumstances.

Data collection

As far as possible, the evaluation was carried out by obtaining direct, independent evidence of the outcomes of the champions' work. This was done by asking for email contacts or phone contacts with key individuals in each area, interviews with professionals involved in the champions' work, and evaluation visits to planned workshops, and to the conference which one of the champions initiated. As a 'user led evaluation, the work involved close liaison with the champions themselves, and their supporter, so that their own insights could be fed into the evaluation report. The project manager also set up with the champions a system for recording and reviewing their own work on an ongoing basis. This enabled the evaluator to have a record of what events the champions had taken part in, what their plans were, and how many people they had reached through their work.

Summary of data for evaluation

The data on which the current report is based is summarised in Tables 6 and 7 below.

Table 4: Interviews with *Putting us first* project personnel (all recorded and transcribed)

Telephone interviews with champions	10
Telephone interviews with supporter	2
Face-to-face interviews with champions	4
Total	16

Table 5: Feedback from participants at champions' events

Face-to-face interviews with participants at conference	16
Interview with professionals at other events	1
Emailed comments from those who had attended events	3
Secondary data provided by emails or other comments passed on by champions	6
Total	26

Additionally, this report has used the self-evaluation and review forms that all four of the champions kept, as well as their own running log of their work. They all kept in touch with the project manager on a frequent basis, and so their emails as well are a source of evidence about their plans, aspirations and feelings about the project as it progressed.

Analysis of evaluation data

The analysis of data was carried out using a thematic approach, in which transcripts of data were scanned for emerging themes. This was done on an open and iterative basis, so that the benefits and problems in the project could emerge from the actual perceptions of all the project participants.

The first round of data was analysed as an interim evaluation report, and discussed with the whole project team at a management meeting half way through the champions' phase. Further plans for evaluation activities were then put into place for the second half of the champions' phase.

The final report was planned so that it fitted alongside the report of the whole *Putting us first* project, and was particularly concerned to draw out the lessons learnt from the champions' phase, so that future work to recruit personalisation champions from mental health service users could benefit from the experiences of the *Putting us first* project.

Appendix B - Role description for service user champions

The purpose of this role is to increase the uptake of personal budgets for people with mental health support needs. You will do this by undertaking training and project work in your local area/region, by delivering training to service users and professionals and also undertake specific project work.

By being a champion we will expect that you will be able to keep up to date with personalisation in mental health, and be able to answer queries about it.

This is what you will be doing:

- Minimum 10 days work spread over a six month period from September 2009 to February 2010
- Delivering training to service users and professionals and others (as appropriate) about personalisation in mental health
- Undertake specific project work in your area aimed at increasing the uptake of personal budgets in mental health
- Networking with existing personal budget fora and key individuals making personal budgets a reality
- Collecting data and maintaining records as required
- Developing links with statutory mental health services (Community Mental Health Teams, recovery teams) and direct payment support services
- Attending meetings as necessary
- Receiving supervision as agreed
- Writing reports on the progress of your work
- Attend training in central London. To be discussed with those recruited

Appendix C - Summary of feedback from regional conference

The conference was the idea of one of the service user champions. A Conference Working Group was established to help the champion organise the conference. The main goal of the conference was to inform and involve more people in Direct Payments and personalisation.

The regional conference was held in South Normanton's Postmill Centre, Derbyshire on 15th March 2010.

67% of the delegates had attended the conference to find out more about personalisation; 24% attended to meet others and network and 9% cheekily said they had attended for a free lunch!

7% of delegates said that before the conference their knowledge of personalisation was very good, however after the day 16% now said their knowledge was very good. For those whose knowledge was good 34% of delegates felt that before the conference this was the case, yet after this had increased to 59%. This trend continues with all levels increasing upwards in knowledge. Before the conference 12% of the delegates said their knowledge was very poor, however after the conference this had fallen to 3%.

85% of delegates said they would know where to get more information. However of the 15% of delegates who didn't know where to get more information; all had said their personal knowledge had increased.

75% of delegates found the style of the conference very good or good. 3% found the style of the conference poor.

74% of the delegates rated the issues covered in the conference as good or very good, 21% neither good nor poor, whilst 3% rated the issues covered as very poor.

Appendix D - Links to resources

Personalisation in mental health: Breaking down the barriers. A guide for care coordinators

Heslop, P. and Williams, V. (2009)

http://www.mind.org.uk/assets/0000/2166/putting_us_first_overcoming.pdf

Personalisation in mental health: A review of the evidence

Heslop, P. and Williams, V. (2009)

http://www.mind.org.uk/assets/0000/2164/putting_us_first_personalisation.pdf

Creating a vision: Views of personalisation from people who use mental health services

Heslop, P. and Williams, V. (2009)

http://www.mind.org.uk/assets/0000/3856/Creating_a_vision.pdf

Direct Payments for mental health service users and survivors

A practical guide to Direct Payments in mental health - written before the moves towards Personal Budgets but still relevant.

www.ilsyork.org.uk/resources/NCIL-guides.php#guide-tosome-key-issues

In control

The *In control* website is packed with useful guidance, information, and resources about self-directed support for all service users, including those who have mental health support needs. It includes individual stories and video clips.

www.in-control.org.uk/site/INCO/Templates/Home.aspx?pageid=1&cc=GB

Individual stories of using Personal Budgets in mental health

Inspiring, illustrative stories from individuals who have used Personal Budgets to support their mental health needs.

www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/MentalHealth/?parent=2737&child=5126

Life and support plan: a guide for the individual budget pilot sites

A practical guide, with pages to photocopy for individual service users, in order to develop their own support plan.

www.supportplanning.org/Support_Planning_Downloads/SP_06Life_and_Support_Plan.pdf

National centre for independent living

The NCIL website keeps a list of all Direct Payment support schemes. You can look up the scheme in your own area, if you do not already know where it is based.

www.ncil.org.uk/directory.asp

Personalisation self-assessment tool

This tool is for local councils with social services responsibilities with partners (such as mental health trusts). It aims to help them better understand what is required to transform social care systems from current models to a 'self-directed support' model that will support the delivery of the personalisation agenda.

<http://self-assess.personalisation.org.uk/csips/>

Personalisation toolkit

The personalisation toolkit is an online resource to support councils to begin to plan and deliver the transformation of their social care systems, as set out in Putting People First.

www.dhcarenetworks.org.uk/Personalisation/PersonalisationToolkit/

Paths to personalisation

A National Mental Health Development Unit resource. It provides information about what personalisation means for mental health services and supports, offers examples of what needs to be in place to make things work, and provides pointers to good practice and sources of advice and information.

www.pathstopersonalisation.org.uk

Who we are

Mind

Mind has been speaking out for better mental health for 60 years. We work in partnership with around 200 local Mind associations to directly improve the lives of people with experience of mental distress. Mental distress affects people from every ethnic background and walk of life – one in four people experience mental distress at some time in their lives and a third of all GP visits relate to mental health.

Mind believes everyone is entitled to the care they need in order to live a full life and to play their full part in society. Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively and with respect.

Mind is an independent charity supported by your donations. We campaign to influence Government policy and legislation, work closely with the media and are the first source of unbiased, independent mental health information via our publications, website www.mind.org.uk and phone service *MindinfoLine* 0845 766 0163.

Norah Fry Research Centre

Norah Fry Research Centre was established in 1988, and 2009 marks a celebration of 21 years of continuous research activity. Its principal interests are in the area of social and policy-related research.

The Centre aims to make a positive difference to the lives of disabled children, young people and adults – and works with disabled people, including people with mental health support needs, to support them in taking part in research and development.

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Southampton Centre for Independent Living

9–19 Rose Road
Southampton SO14 6TE
T: 023 80330982
w: www.southamptoncil.co.uk

HASCAS

11–13 Cavendish Square
London W1G 0AN
T: 020 7307 2892
w: www.hascas.org.uk

UCLAN

University of Central Lancashire
Preston, Lancashire PR1 2HE
T: 01772 201 201
w: www.uclan.ac.uk

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