Working towards Person-Centred Support: a local case study



Karen Postle, Suzy Croft, Jennie Fleming, Peter Beresford, Catherine Bewley, Fran Branfield, Michael Glynn

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We would like to thank all the service users, practitioners, managers, trainers, colleagues and friends who took part in this work and supported us to do it. Without you this Project would not have happened and this guide could not have been written. We hope this guide is useful in making person-centred support happen for all service users.





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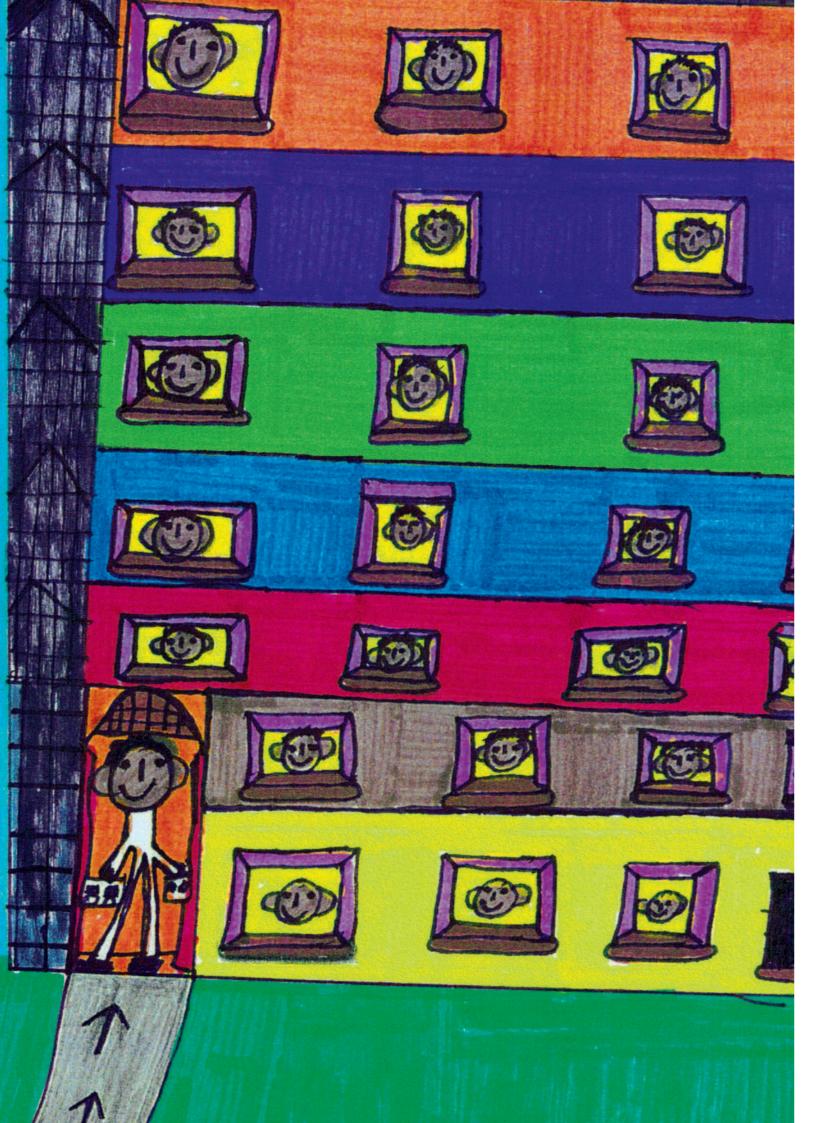
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Foreword

When I first became disabled, some 16 years ago, virtually all social care was provided on a 'one size fits all' basis. Whether it was residential, day or homecare, what was provided was based more around the resources available than around service users' needs, let alone their preferences. If they were living at home, people with physical impairments couldn't choose when they got up or went to bed; they had to fit in with spaces on the homecare team's timetable. If in residential care, service users who were physically impaired couldn't choose who would help them perform the most intimate of personal care; we relied on whoever was on duty that day. Many workers tried to broaden the options for service users within the framework, but no one seriously tried to challenge the framework itself. That's the way social care had been organised for years, everyone had got used to it, or at least accepted the status quo, with a bit of tinkering at the edges. Decision-making was definitely top-down.

And so it was with day provision. With a few worthy exceptions, where people learnt some new skills and had the occasional say into what was on offer, the service user knew, by what day of the week it was, what they could expect, including what was for lunch. There's nothing wrong with predictability – many vulnerable people feel reassured by having a stable routine – as long as you're choosing it, rather having it forced upon you.

Apart from anything else, this report shows how some people's thinking in adult social care has changed. For the service users, it documents a practical example of 'Nothing about Us without Us', meaning that service users need to be involved at every level of decision-making, and for members of staff, that they should not feel disempowered or de-skilled by sharing decision-making, but also need to be involved in the process of change.

At the time of writing, both cuts in budgets and the personalisation agenda itself are seen as real threats to day provision, and, for some people, individually tailored activities are probably the best option. But for many others, perhaps the majority of service users, day provision is the most accessible way to meet with other people who share their disadvantages, for support and education, and an easier way to join the life of their wider community, or even to encourage the community to join them.

For policymakers and practitioners, this report is a template for the development of personalised services, involving the stakeholders with most to gain and lose – service users and front-line workers.

Simon Heng Service User, Disability Rights activist and writer for Community Care



Introduction

This report is one of a series linked with the national Standards We Expect Project supported by the Joseph Rowntree Foundation. The purpose of this national project was to develop person-centred support or 'personalisation' in social care and other services, in line with the 'standards' that service users want. It focused particularly on including the views and experience of people as service users, informal carers and face-to-face practitioners. The aim was to find out what barriers were getting in the way of disabled people and service users having the services and support they wanted and how these barriers could be overcome.

The Project was particularly timely because successive governments have emphasised that they want to move to more 'personalised' services that ensure people greater choice and control. This report also has a particular importance for this Project because its focus is on trying to make change in local services. The underpinning aim of the Standards We Expect Project was to bring about change and improvement in line with the rights and preferences of service users.

Talking about positive change and trying in practice to make it happen tend to be two rather different things. The rhetoric, particularly in social care, often seems to have been more evident than the reality.

That's why we hope that this case study may be of wider relevance and value to people working to achieve more person-centred support in social care and beyond. It is not offered as a 'success story' or picture of 'how to do it'. Rather it should be read as a real world example of the kind of issues and ambiguities that there can be when agencies and authorities decide to make change; what can help and what can hinder. We hope that this will mean that the report can serve as a useful resource to organisations, teams and individuals working to make their own change to improve the lives and support of health and social care service users.

One of the key issues the local case study highlights is that if policymakers truly want to achieve real 'person-centred support' or personalisation, then they will have to go about it in a person-centred way. The process will need to be a participatory one, fully and equally engaging service users, unpaid carers and face-to-face practitioners.

A local case study of change

In this report, we look at how change was managed in a local authority day centre and what helped and hindered making that change towards person-centred support in a person-centred way. To ensure the anonymity of the service that took part in our project, we have identified the area in which it was located as 'Grandshire', a large county with both urban and rural areas.

This day Centre had originally been a traditional one for adults with physical and sensory impairments. It opened 35 years ago and is located near the Centre of the city. It is a drab single storey building, which is rather unwelcoming in appearance. It was clear that the local authority had not invested very much in its upkeep over the years. The Centre was attended by service users whose places there had been arranged by social services and also more recently, by people who accessed its facilities directly.

The day centre and change

At the time the Standards We Expect Project took place, the day Centre had already recently undergone considerable change. This started four years previously when an IT (information technology) 'learning station' from the local further education college moved in to the building. This opened up the possibility of the Centre being used by the wider community, for example the Workers' Educational Association (WEA), adult education, a local disability information service and the local deaf children's society.

The Centre was also used for meetings by various local voluntary groups during the evenings. Centre managers were exploring links with other organisations, such as Age Concern/Age UK, who were seen as being interested in overcoming barriers to working in person-centred ways. The Centre had also recently taken part in a European 'e-learning' project.

Other changes which were being considered included the possibility of using transport differently so that people could pay to use it to come in when they wanted to, as well as on allocated days, and linking with other clubs and facilities for disabled people and people using mental health services locally.

Further major change at the Centre had been in developing the role of the former 'co-ordinators of creative activity'. They had become 'Disability Development Workers', (DDWs). They now had a very different role which involved working much more with people within their communities and homes, rather than at the Centre. The aim of the Disability Development Workers was to link people up with one another and to work with them to develop resources locally and try to remove barriers to the use of existing community resources, such as leisure facilities.

This meant people no longer had to be taken by transport over long distances to attend the Centre and were able to take part in activities in their local areas, including using regular mainstream community facilities. The DDWs had worked with service users enabling them to start up their own support groups and then withdrawing when

these were self managing. Their information leaflet stated that:

"We exist to ensure that disabled people and their carers in Grandshire have access to information and support and to explore opportunities and choices in their lives."

Disability Development Workers themselves said things like:

"Rather than us bringing services in to a person it's starting with the person around what that particular person's needs are and matching the services with their needs rather than the other way round."

Managers explained that there had been some difficulties with a minority of the co-ordinators of creative activity in adapting to the new role, but the current workforce were committed to it, as they made clear in their own comments.

It was clear that all these changes had come about because without them, the Centre could not have survived. The emphasis on community care and the growth in use of direct payments, enabling service users to choose and purchase their own services and support, together with changes in societal attitudes, disability rights legislation and disabled people's own views of what is acceptable for them, have all combined to make day Centres,

with their unwelcome tendency to lump people together, a less attractive and inappropriate option. They have long been subject to criticism for segregating disabled people away from their communities (Barnes, 1990). It was therefore imperative that the Centre changed and adapted and there was a strong sense that change had to be kept under constant review and the Centre could not afford to 'rest on its laurels':

"We've felt confident about what we're doing around person-centred approaches, about empowering people, moving things on and moving services on." Manager

"If we stuck to, 'This is a Centre for disabled people. Full stop' this place probably wouldn't have a future." **Manager**

A crucial change, which was proposed soon after The Standards We Expect Project began, was that of incorporating a children and families Centre into the day Centre. This was a very rapid change, taking place within less than a year. There were understandable concerns that this change of use would represent a threat to existing Centre users, especially as, traditionally, services for children and families have taken priority in local authorities' funding decisions:

"We want to ensure we don't give away a lot of our resources." Manager

The key was seen as meeting people's needs, rather than preserving the Centre for its own sake. It was seen that there could be considerable potential for the Centre's use to be changed and, for example, for people using the Centre to become involved in projects such as children's reading schemes if they wanted to. Integration aspects ... Adults helping children to learn to read ... If you've actually got disabled people who can actively make relationships with the children through working with them then that's gonna affect attitudes for the children and opportunities for disabled people as well. **Senior Manager**

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"The cuckoo effect ... the cuckoo in the nest ... they'll come in and they'll kick us out because children and families can have a reputation of being a bit precious." Manager

Thus managers at the Centre took the view that the best chance for continuing would be a change to wider use. However they said that a guiding principle in undertaking the changes involved being responsive to service users and not just telling them what was going on. They told us that the Centre Users' Management Committee was fully behind the change:

- "They (Management Committee) are absolutely 100% with it ... people are absolutely with the kind of changes we are doing ... they see that the best chance that this place has got of providing a wide range of services and opportunities for disabled people or whoever is by embracing these partnerships and the wider community." Manager
- "At the moment we're looking at becoming a children and families' Centre as well as well as a resource Centre for disabled. Lots in the pipeline at the moment about that ... That was all discussed at management committee meetings." Service user

"But it'll be a change for the good won't it? That means that the Centre keeps going." **Service user**

Consulting with service users and staff

The managers sought to find out what people using the Centre wanted through the Service Users Management Committee. This committee approved all decisions regarding the Centre's use and had a right of veto. Staff views were gathered through the use of regular appraisals and staff meetings:

- "We have a review once a year and you can go and talk about anything that you're bothered about or anything. If it needs doing about it, they'll do it." **Service user**
- "These people here on the (management) committee, they run this place. We run it, through this works committee. Whatever. Tremendous." **Service user**
- "It's a Centre run by the users as well as the people that work here. There's an internal committee, management committee which is run by ... which is mainly users of the Centre themselves." **Service user**
- "And the manager's always seeking your opinion, isn't he?" **Service user**

I think that is why we have tried to evolve with the times. At one time it could have been ... there's a lot of Centres closing because they don't meet particular needs ... or things that people need to do there ... We could have been one of the casualties, we could have had to close but because we invited in Learn Direct and the general public, made it more accessible for other people not just disabled people ... now children and families – It's evolving all the time. Hopefully it'll stay open. Service user

We are always informed of anything and everything, we are always asked our opinions, whether we have any direct control when it comes to that ... that's a thing I really like, the care of the staff is just as high quality as the care of the clients.

Senior Manager

- "Any decision that happens within the Centre is passed through the management committee. If we don't like the idea it doesn't happen." **Service user**
- "He never makes a decision without consulting all the staff. It isn't just a few of us. He appreciates that what might impact more on one area of staff can also impact on others without immediately recognising that, but he sees that. It's a fantastic place to be." **Centre staff member**
- "We are always informed of anything and everything, we are always asked our opinions, whether we have any direct control when it comes to that ... that's a thing I really like, the care of the staff is just as high quality as the care of the clients." **Centre staff member**

It was clear that, because of its history, the Centre was now trying to meet the differing needs of a very varied group of people. These fell into three broad groups:

- People who have very high support needs and for whom there were no other suitable and/ or available options.
- People who have been attending for a long time and were accustomed to the way the Centre used to be.
- People who use the Centre for specific things.

From talking with the Centre Management Committee and other service users there were mixed views about whether the Centre was still catering for people's needs to the same extent as previously. Generally people felt they were getting a good service:

- "We've got so much going on. That wall out there (notice board with courses on it) proves it." **Service user**
- "Tremendous choice. If you go outside you'll see on the board. I go to six different activities." **Service user**

The changes to the Centre went ahead and the children's Centre was officially opened in March 2008. As managers had intended, the improvements to the Centre had acted as a lever for some further renovation and the whole main corridor had been repainted and was much brighter and more welcoming. The courtyard had been refurbished and the cafeteria was being re-vamped. Some Centre users were mixing with families and one took a small part in the opening ceremony, presenting prizes for children who had won a competition to re-name the café. There was some sharing of resources and courses.¹

From the Centre users, staff and managers with whom we subsequently spoke there had apparently been no difficulties since the children's Centre opened. The impression gained was of a Centre, which was developing much more as a community Centre, which disabled people could use, rather than as a separate Centre for disabled people alone, thereby breaking down barriers.

¹ Shared usage can raise issues regarding safeguarding; at the Centre, this is addressed in a number of different ways. Children are always accompanied by their parents, carers or staff, also the doors used for their activities have key pads so unauthorized people cannot enter. All Centre staff had safeguarding training, and staff and volunteers have CRB checks. A further generalized security measure is the CCTV coverage of the building.



Enabling change

From all our discussions with people using the Centre, members of the local Coalition of Disabled People, Centre staff and managers, the following factors emerged as being of central importance in enabling change, which may be inevitable, to happen in person-centred ways.

There was broad agreement from managers, staff, Centre users and members of the coalition of disabled people about what working in 'person-centred' ways meant:

So that the care you receive is adapted to your needs. Service user

I try to bring out what they could do to make the most of their time here. **Centre staff member**

Every other day service or Centre I have been to, it's usually mainly just dealing with the physical care side of things. Whereas here it isn't that at all, it's emotional and everything, emotional, educational, you do find out more about people this way, what their needs and wants are. **Centre staff member**

Members come first, they are listened to, respected, treated with dignity. We offer a very wide choice, which is person led rather than Centre led. **Centre staff member**

We're coming along to say, 'What is it I can help you with?'... It's bottom up rather than top down. Manager

This shared understanding undoubtedly contributed to achieving change in ways which have continued to keep Centre users' needs central in planning and development.

Involving all stakeholders

The level of consultation with service users and staff appeared to have been very good indeed. As outlined above, there were regular meetings with both Centre users and staff. Staff had formal team meetings on a regular basis and met briefly together every morning. Staff said they received regular supervision which was supportive and positive:

- "The best thing is the management of the place, it's terrific, (two names) are great managers. There is a nice friendly atmosphere, not at all petty. Everyone works together as a team. There is good back up too. We have a staff meeting every day. Supervision is very good, at least every two months." **Centre staff member**
- "(We have) weekly team meetings but every morning we have a chatty meeting that is good, it doesn't allow things to fester and go wrong. The input is pretty good actually, our manager is very good, very down to earth, genuinely believe that if there was a situation when people fundamentally disagree with (name of manager), he would listen to it and act accordingly. At a lot of places you become a manager and lose touch with your staff but not here, it's very democratic. A terrific place to work. No bad vibes, very out in the open." Centre staff member

From our discussions with both of these groups, staff and service users, we gained the impression that the Centre was well managed with people having high regard for the management and staff and confidence in them. Centre users and staff felt that they were listened to and their opinions taken seriously:

- "You don't want to worry people, but keeping people as fully informed as you can with a degree of ownership over it and an understanding of why the changes are necessary." Manager
- "The staff are fantastic, it's a joy to come here, we all look forward to it, you know you are safe ... and you're meeting people." **Service user, others agreeing**
- "We are always involved, staff and members equally, the commitment and the dedication of the staff here is something I think is fantastic." **Centre staff member**

People using the Centre felt confident that the changes would not have gone ahead without their agreement and they were happy with the changes:

"I had a conversation with (name) who's the manager of the Centre about the children and families thing that's happened and I said to him, 'Being perfectly honest if, as a committee, we had turned round and said to you, 'We don't want that ... we don't feel that that's the way forward' would you have still gone ahead with it?' and he said, 'No. I'd have tried saying to you, 'Well, you know, this is the reason why we want to do it and these are the benefits that you'll probably get' but if you'd have said 'No' that would have been it. It would have been squashed." **Service user**

Centre users and staff felt that they were listened to and their opinions taken seriously.

We're looking to certainly ensure that those people (with greatest support needs) don't lose out ... In future the care staff that we've got will be very much targeted towards those individuals who are eligible for services and have got those care needs ... the care hours that we've got will be targeted to those people who need them the most. Manager

Support for staff

Good systems for the support of staff – both to ensure their views are heard, but also to help them to understand and manage the change – was seen by workers as very important:

- "The support and supervision from the management is second to none."

 Centre staff member
- "At the daily staff meetings people could talk about anything you want to bring to the table." **Centre staff member**

The open and approachable style taken by the manager was seen as a key part of this:

"(The manager) is that sort of person you can chat to him about anything at any time." **Centre staff member**

Managers having a flexible approach

In this case managers neither allowed the Centre to simply close, nor fought to keep it open at all costs. They were in agreement about the need for change in order for the Centre to retain its viability as somewhere for people who, regardless of whatever other initiatives could be provided within the community, would need the high level of personal support provided within a day Centre setting.

It was also clear that some people who currently received a lower level of support would find that this was reduced, but were seen as nonetheless able to benefit from the changes at the Centre and from the fact that it was still in operation. "It is about adapting and changing otherwise we might not have a building at all." **Manager**

Managers also recognised there were some groups such as disabled people who are parents, and also disabled children, whose needs were not being well served by the Centre and it was hoped that flexibility within the Centre would benefit them.

Openness and honesty throughout the process

It was apparent from comments from Centre users and staff that they considered the managers had been open and honest in their discussions about forthcoming changes. The Centre manager had appreciated that people understandably viewed it as 'our Centre' and resented the initial changes which opened it up to the wider community. He explained how he had struggled to maintain a balance between wanting to persuade people to see what changes needed to take place to keep the Centre open and 'disenfranchising' people by reducing their choices:

- "We want to challenge that 'our Centre'..., I don't mean that in an aggressive way... because that has been part of the problem in the past." Manager
- "I hope it's been a good example of managing a change situation without disenfranchising the existing users." Manager

Managers and staff being open in their approach to change

In our discussions with managers we found them open to considering ways of handling the changes being made to ensure that they remained personcentred in their approaches. For example, we discussed with them the possibility of there being unintended consequences from the changes (Rogers, 1983) and they readily considered what strategies could be put in place to deal with such eventualities.

The staff's attitude to the service user-led training workshops they had attended, run as part of the Standard We Expect Project also indicated to us that they were open to reflecting on the way they worked and considering changes needed in order to work in more person-centred ways:

"It's like a wake up call."

Centre staff member

Some managers and some staff voiced concerns that paradoxically although people using the Centre wanted it to remain open, its very existence could be impeding their development and independence. This echoes Barnes' (1990) criticism of day Centres for young people with physical impairment where he argued that day Centres impeded, rather than developed independence: "Without any doubt we are making people more dependent than they need to be." Manager

"We had a group of older people who used to sit in the lounge and expected to be waited on and entertained, they expected to have bingo. You tended to get a backlash." **Centre staff member**

- "Other people who don't need really need a service, probably don't need to come here." **Centre staff member**
- "For some people they stay with the same service. Frustrating for people you know who need the service."

 Centre staff member

This is a very important issue and it was discussed in the Standards We Expect Project's interim report following the first get together it organised, which brought together people from different local partner projects. (Glynn et al, 2008).

Consideration must be given to what is understood by 'choice', a term which is often and lightly used in the rhetoric of Government publications (Independence, Well-Being and Choice: Our vision for the future of adult social care, (DH 2005) Independent Living Strategy, (ODI 2008) and Shaping the Future of Care Together, (DH 2009). We need to look carefully at the extent to which people using services actually have real and informed choice.

Clearly the questions raised here cannot be addressed overnight, but there does seem to be a parallel with what consortium members found in other sites. For example in residential care provision, people sometimes seemed to be very happy to remain where they were but this may well have been because they had never had the opportunity to explore alternatives. There is a very real risk that people become institutionalised and cease to be aware of alternatives, consider them, or to see them as viable (Goffman 1961).

There is a very real risk that people become institutionalised and cease to be aware of alternatives, consider them, or to see them as viable.

The barriers

While the changes at the Centre appeared to have been managed successfully and in ways which remained person-Centred, there were, nonetheless, lessons to be learned about handling change in the future. We identified a number of barriers. These included five that seem particularly significant:

Top-down policies and token involvement

Clearly, in the example which we have focused on here, a decision was made at a senior level that the Centre should change its use and, fundamentally, that suggestion did not come from the people using the Centre themselves. Without the proper involvement of people using services at all levels of decision-making, changes will continue to be made in this way and can never be fully person-centred. (Finkelstein, 2004). At least, as we have seen, in this instance, having fixed on a policy change, every effort was made to involve people in it and make it possible for them to have some say in the form it ultimately took.

We were, however, pleased to note that the managers at the Centre had pressed for and achieved a user-led commissioning strategy which was to be jointly written with the local coalition of disabled people and would have a jointly chaired board. This indicated a real development in user involvement and also, importantly, a relationship of trust between senior managers and the coalition. This will hopefully impact on decision making in the future.

Not knowing about the options

There is a tension here which needs to be acknowledged. While day Centres can be seen as providing a service which, as indicated above, may no longer be appropriate for many disabled people's needs, they nonetheless provide a service which, for some people which is still valued and which could not easily be obtained elsewhere.

There are complex issues here. Clearly it is difficult if not impossible to know, from the views of people attending the Centre, whether they were keen to remain there because it was all they had ever known and they have not been sufficiently empowered to be aware of or consider other opportunities, or whether they were making a fully informed choice. Certainly the people we spoke to were gaining real benefits from attending and so this remains an area of uncertainty:

"I was in quite a depressive state ... I came on a visit ... It is an absolute lifeline, really is. I can honestly say it's saved my life. I was getting to the state where I probably may have thought of doing something really stupid. Fact that I could get out and meet like minded people, that have not all got the same thing wrong but very similar, facing most of the same difficulties. I had a young family, husband working, I could air things. These people are fantastic. The friends I've made here are fantastic ... If this place was ever to shut there would be uproar." Service user

In our second interview with people using the Centre they told us that one of the DDWs was due to come to a meeting with Centre users to explain their role so it was hoped that this would bridge any communication gaps.

Only some of the service users interviewed seemed to know about the role of the Disability Development Workers who could, potentially, be very effective in enabling them to explore choices outside of the Centre and this, together with DDWs apparently not having always been successful in finding options for these people outside of the Centre, may have influenced such Centre users' views about potential options. It was difficult to know why this knowledge was so patchy.

In our second interview with people using the Centre they told us that one of the DDWs was due to come to a meeting with Centre users to explain their role so it was hoped that this would bridge any communication gaps:

- "They ask you what you would like, what is going on in your home life, what's going in the Centre, if there's anything you'd like to build on what you're already doing or any other needs at home. If they can implement it, they do so. I asked if I could learn to speak French, they found somewhere I might have been able to go, but it wasn't accessible in the end." **Service user**
- "Oh I didn't realise. I don't think about titles, they are just staff." Two service users discussing DDWs
- "It may have been a DDW who helped me with a voluntary placement at a school for disabled children, doing databases for them. Unfortunately due to the way my thing was I had to give it up but while I did it, it was really good ... If there is outside work to be had and you're capable and willing, they will sort that out for you." **Service user**

Hearing *all* voices

While it was clear that, as outlined above, managers were making considerable efforts to hear people's views, we had some concerns about the extent to which the views of those who held differing, minority opinions were heard. When interviewing the Centre management committee and other Centre users, for example, it became apparent that there was a lack of agreement on provisions at the Centre:

"It's not too bad. I have been coming to the Centre for a good amount of years now here. From what I've noticed from the past from when I first started... it doesn't seem to have much stuff for people like myself to do and what have you. Now there's not much going."

"They've got so much going on."

Disagreement between two service users about the amount of activities

We noticed that service users holding these minority views were not listened to by other service users and were effectively silenced. On one occasion, we witnessed a dissenting voice being silenced by someone talking over them (to ask if it was someone's transport which had arrived outside)!

Two people spoke to us after the interview to explain that they didn't see things the same way as the majority. One person told us they were very sorry that the gardening and bird watching groups had finished because people had got pleasure and therapeutic value from it. We did wonder whether voicing any criticisms to us, as 'outsiders' could be seen as detrimental to the Centre, particularly if its future was precarious:

"I resent (name) saying what he said to an outsider cos if he hasn't got anything to do that's his fault. Not anybody else. I have six groups I go to here and he could go to other groups if he wanted to."

Service user, others in the group voiced agreement

We were pleased to note that the managers at the Centre had pressed for and achieved a user-led commissioning strategy which was to be jointly written with the local coalition of disabled people.

Some staff also indicated to us that, although they thought that consultation was good, they were concerned that the Management Committee could be more proactive:

"The committee that is run by elected members here, that probably hasn't got as much teeth as maybe the manager would like, one or two people who are very.. speak out, very proactive, a lot go to the meeting and then to the next meeting and nothing happens in the middle" **Centre staff member**

As we have discussed elsewhere it is important that people using services are not solely in the position of being consulted but can also have a more active and equal involvement (Carter and Beresford, 2000).

Appropriate communication strategies

We were concerned that a man with a visual impairment who joined the discussion group at the Centre had not been given any prior information about the Project. We had sent written information sheets and asked whether information was needed in other formats, but had not been alerted to his specific

communication needs. One member of staff had highlighted that the Centre could do more for people with visual impairments:

"It would be good to have more equipment and more things, like minutes in Braille." Centre staff member

Such access issues for all must be addressed if person-centred support is to operate for all and not just those who can most readily be reached or communicated with.

Remaining alert to the need for change

Following the training workshop for staff provided by the Standards We Expect Project, a suggestion box had been installed in the Centre's canteen. We had actually raised this as a possibility in our report back to staff some ten months previously but that had not been actioned. The box was brightly coloured and clearly labelled, in a prominent position and accessible by people using wheelchairs. It did not, however, have any information about its use, what would happen to suggestions made or whether they could be made anonymously. Clearly people need to know if and how their comments may be used and if there is a point to offering them.

Wider implications

The value of this local case study lies not only in the evidence it offers about how change may actually happen in a real life situation. It also offers insights and helpful implications for getting this right more generally. Here we set out some of the most striking implications that emerged for us from this local experience and the lessons that they may offer.

- 1. Consideration needs to be given to the ways in which people using services/facilities can generate their own ideas for change, taking a proactive rather than a reactive role. This would appear to demand closer links between service users and policy makers to avoid the perpetuation of 'top down' decision making.
- 2. The extension of personalised support through direct payments and personal/individual budgets is likely to have further implications for how and whether disabled people use day Centres. People may choose not to use them at all or Centres may increasingly be able to offer the kind of facilities/activities which people want to access. Such facilities/activities may well be community-based rather than solely for use by one group like disabled or older people. This has implications for people's involvement in planning and provision of services and for how services are commissioned. This is particularly relevant as day Centres are now increasingly facing closure in the face of severe spending cuts.
- 3. Meeting the needs, in person-centred ways, of a diverse group of people is a complex and difficult task, requiring considerable time and skill and a variety of approaches. The opportunity for service users to talk with other people, who have experienced different life choices, is essential.
- 4. Careful consideration must be given to what is understood by 'choice' and the extent to which people using services actually have informed choice. Again, hearing others' experiences is essential and needs to be facilitated and encouraged.

- 5. Mapping principles of involvement is vital to ensure that people's strengths can be built on and barriers avoided. In our discussions with managers we thought that it was better to consider principles rather than specifics. For example, if a principle is 'listening', then meetings can be organised to meet service users' access requirements.
- 6. It is important to consider outcomes, not just outputs. This may well include what could be considered 'soft' outcomes which may be harder to demonstrate but are nonetheless very important for people using services.
- 7. Much has been written about the management of change but there is very little, if anything, which considers this from the perspective of someone using services. This needs to be addressed urgently if organisations and policymakers are serious about user involvement.
- 8. Managers and staff need to get feedback on and analyse their skills, qualities and ways of working with people when these have generated successful person-centred outcomes because they can all too easily be taken for granted.
- 9. Last but definitely not least, staff who feel valued are more likely to be able to value and empower others. The effective involvement and empowerment of service users is not at odds with the empowerment and involvement of staff. Instead where this happens, it is much more likely to happen.

Conclusions

Moves to personalisation and 'self-directed support' in health and social care through receipt of personal budgets seem often to be presented as the polar opposite of continued reliance on traditional day Centres. Day Centres have often been stereotyped by policymakers as obsolete and perpetuating exclusion and segregation. The argument that they lump people together and separate them from mainstream provision is a powerful one. Current social policy is for disinvestment from day provision and their closure.

Yet ironically, given that it is often in service users' names that this move has been justified, many service users supported by practitioners oppose the closure of such day Centres. They argue that they offer safe space where they can be together with others with similar experience, where they can regain confidence and skills. Such day services can serve as the springboard to new opportunities. They are a much more positive option in reality for many people who may face rejection and ridicule in the wider world and cannot afford the high prices of life on the high street.

What is interesting about this study is that it describes an attempt by a local authority to make a day service more inclusive and integrated in line with broader policy pressures, while still trying to listen to what its service users were saying. This is not a simple success story. There are few of those in the real world of social care, although the search always seems to go on as if a magic bullet really may be found. It was still the service rather than the service user who initiated the change. It is not clear how assertive service users have been in expressing their views and demands. Issues of choice and informed choice still need to be addressed much more carefully.

The new role of the 'Disability Development Workers' (DDWs), raises as many questions as answers. They may be able to reach out to engage service users and help them be part of the mainstream, but do they also serve as a kind of 'social worker on the cheap', undercutting the role of the professional practitioner and putting it at risk?

At the same time, as well as highlighting some of the difficulties of moving to person-centred support in a participatory and inclusive way, this local case study does offer some fresh and helpful insights into how that journey may be more effectively made. The map it offers may be a small one, but it is likely to be helpful to others with a genuine commitment to make the journey, especially if read alongside the other learning coming from the Standards We Expect Project and similar initiatives.

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All website links were correct at 18/1/11

Useful oganisations

Government departments

Department of Constitutional Affairs

Mental Capacity Implementation Team 5th Floor Steel House 11 Tothill Street

London SW1H 9LH Telephone: 020 7210 0037

Email: makingdecisions@dca.gsi.gov.uk www.dca.gov.uk

Department of Health

This website includes a list of all local Independent Mental Capacity Advocate (IMCA) services. For more information about what an IMCA is and a list of all IMCA services across the country, contact: www.dh.gov.uk/mca

Equality commissions

The Equality and Human Rights Commission

Equality and Human Rights Commission (England) Freepost RRLL-GHUX-CTRX Arndale House Arndale Centre Manchester M4 3EQ Telephone: 0845 604 6610 Textphone: 0845 604 6620 Fax: 0845 604 6630 www.equalityhumanrights.com

Equality and Human Rights Commission (Wales) Freepost RRLR-UEYB-UYZL 1st Floor, 3 Callaghan Square Cardiff CF10 5BT Telephone: 0845 604 8810

Equality and Human Rights Commission (**Scotland**) Freepost RRLL-GYLB-UJTA The Optima Building

Textphone: 0845 604 8820

58 Robertson Street Glasgow G2 8DU

Telephone: 0845 604 5510 Textphone: 0845 604 5520

National service user and disabled people's organisations

Shaping Our Lives National User Network BM Box 4845 London WC1N 3XX Telephone: 0845 241 0383 www.shapingourlives.org.uk

SOLNET website of organisations of people

www.solnetwork.org.uk

National Centre for Independent Living

Unit 3.40 Canterbury Court 1-3 Brixton Road London SW9 6DE Telephone: 020 7587

Telephone: 020 7587 1663 Advice Line: 0845 026 4748

Self advocacy

To find your local self advocacy group you can go to the website of the National Forum: www.nationalforum.co.uk

People First

A self advocacy organisation run by people with learning difficulties based in London is: www.people-first.co.uk

Other national organisations

Action for Advocacy PO Box 31856 Lorrimore Square London SE17 3XR Telephone: 020 7820 7868

www.actionforadvocacy.org.uk

Housing Options

Sutton Lane Witney Oxfordshire OX29 5RY Telephone: (0845) 456 1

Stanelaw House

Telephone: (0845) 456 1497 www.housingoptions.org.uk

National Association of Citizen Advice Bureaux

www.nacab.org.uk www.adviceguide.org.uk

National Association for Voluntary and Community Action

The Tower 2 Furnival Square Sheffield S1 4QL Telephone: 0114 2

Telephone: 0114 278 6636 Textphone: 0114 278 7025 www.navca.org.uk

National Brokerage Network

3 The Courtyard Windhill Bishops Stortford Herts CM23 2ND Telephone: 01279 504735 www.nationalbrokeragenetwork.org.uk

www.mationalproxeragemetwork.org.

Excellence Goldings House 2 Hay's Lane London SE1 2HB Telephone: 020 7089 6840 Textphone: 020 7089 6893 www.scie.org.uk

Social Care Institute for

Values Into Action PO Box 59043

www.viauk.org

London E13 3AZ Telephone: 07754 157718

Reports from the Project

The Standards We Expect Project has produced a range of documents about person-centred support written for a variety of people on a variety of topics.

You can find out how to get a hard copy or download a copy from these websites: www.shapingourlives.org.uk www.policypress.co.uk

The website will also tell you how to get Word copies of the documents which can be downloaded for use with computer readers or in large font versions.

Supporting People:

towards a person-centred approach

Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Published by Policy Press 2011

Supporting People:

towards a person-centred approach Findings

Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Published by Joseph Rowntree Foundation 2011

Supporting People:

the big issues

Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Published by Joseph Rowntree Foundation 2011

Supporting People:

a summary in easy words and pictures

Gina Barrett, Maggie Brennan, Dana Brown, Neil Burton, Wenda Gordons and Christina Watkins from People First Lambeth with Hom Saihkay and Catherine Bewley

Person-Centred Support: a guide for service users

Catherine Bewley, Fran Branfield, Michael Glynn, Peter Beresford, Suzy Croft, Jennie Fleming, Karen Postle

Person-Centred Support: a guide to person-centred working for practitioners

Suzy Croft, Catherine Bewley, Peter Beresford, Fran Branfield, Jennie Fleming, Michael Glynn, Karen Postle

Making a Change:

a guide to running successful and accessible workshops and training

Michael Glynn, Fran Branfield, Catherine Bewley, Suzy Croft, Jennie Fleming, Karen Postle

Person-Centred Support: choices for end of life care

Jennie Fleming, Michael Glynn, Rod Griffin, Peter Beresford, Catherine Bewley, Fran Branfield, Suzy Croft, Karen Postle

Working towards Person-Centred Support: a local case study

Karen Postle, Suzy Croft, Jennie Fleming, Peter Beresford, Catherine Bewley, Fran Branfield, Michael Glynn

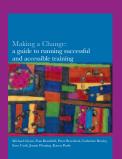


This report is one of a series linked with the national Standards We Expect Project supported by the Joseph Rowntree Foundation. The purpose of this national project was to develop person-centred support in social care and other services, in line with the 'standards' that service users wanted. It focused particularly on including the views and experience of people as service users, informal carers and face-to-face practitioners. The aim was to find out what barriers were getting in the way of disabled people and service users having the services and support they wanted and how these barriers could be overcome.

Also available:



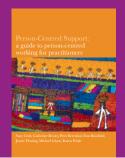
Person-Centred Support: a guide for service users



Making a Change: a guide to running successful and accessible training



Person-Centred Support: choices for end of life care



Person-Centred Support: a guide to person-centred working for practitioners



Supporting People: towards a personcentred approach



