Person-centred support

What service users and practitioners say

Michael Glynn and Peter Beresford with Catherine Bewley, Fran Branfield, Jabeer Butt, Suzy Croft, Kiran Dattani Pitt, Jennie Fleming, Ronny Flynn, Charles Patmore, Karen Postle and Michael Turner.

Opinions of service users, practitioners and managers on person-centred support.

This study examines person-centred support, a key new concern in public services. It does this by bringing together for the first time the views, ideas and experience of service users, face to face practitioners and managers. Government is committed to 'personalisation', 'self-directed support' and 'individual budgets' in social care, aiming for increased choice and control for the people who use services. This is a move away from traditional, 'one-size-fits-all' approaches.

The research asks:

- what person-centred support means to people who use, work in and manage services;

- what barriers exist to making services person-centred; and

- how the obstacles might be overcome.

The report builds on new evidence from the national *Standards We Expect* project, bringing together for the first time direct experience in 20 areas of the UK. These include different service sectors and a wide range of service user groups. The report will be of value and assistance to everyone interested in social care, health and taking forward the new reforms.

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Available in other formats

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Contents

Foreword

Disabled people and others have long argued that it does not make sense to spend money on services which limit people's choices and their opportunities to live ordinary lives.

The alternative – to support people to make choices and to be included – goes under many different names, including 'independent living', 'person-centred services and 'self-directed support'. They are all based on the same principle: if disabled people are to participate and contribute as equal citizens they must have choice and control over the support they need to go about their daily lives.

This is a matter of social justice. It is an issue therefore which is fundamental to the kind of society we are, and the kind of society we want to be.

Moreover, it is essential that the people who depend on services are at the heart of decisions about the design and delivery of those services.

This report starts from that position, by asking service users themselves what person-centred support is, what gets in the way of providing it and what helps. It also fully recognises the role of family carers and the important relationship between service users and those managing and providing services.

'Personalisation' of public services has become fashionable for politicians, policy-makers and providers. This report is a timely reminder that service users have long been arguing for, and designing, person-centred services. Change will only happen if services are shaped by the people who rely on them.

So, an idea which came from service users themselves will only be realised if individuals are empowered to play their full part, not only in determining their own lives but also in the transformation of public services.

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Acknowledgements

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We also want to say thank you to everyone who has taken part in the project sites and been involved in and contributed to the broader network of the Standards We Expect project.

We are grateful to Jean Collins, who was originally a core member of the project team, before moving on from Values Into Action.

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Finally, our thanks to Mark Brookes at Values Into Action for his skilled advice and guidance in developing the accessible summaries included in the report.

All the photographs in this report were taken at the Get Together event by Joanne O'Brien.

All cartoon images were provided by CHANGE picture bank.

Summary

This report includes a lot of information and discussion about person-centred support. It is quite long.
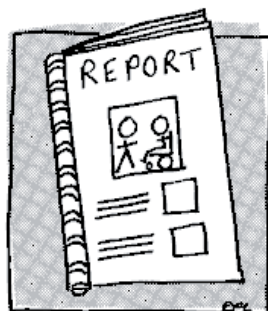
The Standards We Expect project wants to make the most important things in this report accessible for everyone.

We have written a summary for each chapter of the report. The summary uses plain English and pictures to tell you what that chapter is about.
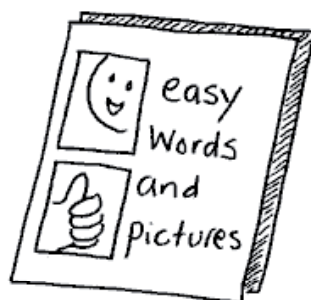
We have put all the summaries for each chapter together here at the start of the report.

For some chapters, the summaries seem long. This is because we have used big letters and lots of space to make it as easy as possible for people to use them.

The summaries follow the same headings as the main report, so you can follow the same main points. Some chapters have lots of points.

We hope these summaries help as many people as possible to find out about person-centred planning (PCP) and our work.

What service users and practitioners say

This summary tells you about the Standards We Expect project.

What is this project about?

The Standards We Expect project is a three-year research and development project. It is paid for by the Joseph Rowntree Foundation. The project started in January 2006 and ends in December 2008.

The project is about person-centred services. This means services that put the person at the centre.

The project is also about service users. This means anyone who gets a service paid for by Social Services, including:

- people of all ages and all backgrounds;

- people with all sorts of physical and sensory impairments;

- people with learning difficulties;

- people with mental health difficulties;

- people who are dying who need services;

- people who are homeless;

- people with drug and alcohol problems.

More and more people think that service users should be at the centre of services and how they develop.

Service users have set up their own organisations. They talk about 'the social model of disability'. This means looking at how services and society stop disabled people being equal and having control over their own lives.

Some people are talking about 'self-directed support'. This means service users saying what support they need and how money should be spent to get that support.

Who is involved in the project?

Eight organisations are 'partner sites' in the project. They are working closely with the project team. The project works with service users, staff and managers in each partner site.

Some sites have a mix of ethnic groups, some have all white members, and one site has mostly Pakistani members.

There are twelve other organisations involved in the project, also including people from a range of backgrounds. They are part of a network learning and sharing together.

There are eleven people on the project team. One person is the project worker, and some team members are service users. Four members of the group are from black and minority ethnic communities.

Some members of the team are there as individuals, and others are from four organisations:

- Shaping Our Lives;

- De Montfort University;

- Brunel University;

- Values Into Action.

The project is asking three questions:

- What does 'person-centred support' really mean?

- What are the main difficulties that stop person-centred support?

- How can these difficulties be got over?

Getting people together: sharing views

The people involved in this project and how we all got together to share our ideas and experiences.

The Get Together day

In November 2006, the project ran a big Get Together day in London for people from the 20 organisations involved in the project.

The Get Together event brought together service users, staff and managers.

The project also worked hard to include:

• people from black and minority ethnic communities;

• people who communicate differently;

• people with learning difficulties who have high support needs;

• older people, including very old people;

• people living in residential homes;

• people who are stuck in their own homes.

The Get Together day helped people:

- get to know each other and learn from each other;

- share experiences and ideas;

- find out more about person-centred support and feel more energy about it;

- say what they wanted from the project.

The project put a lot of effort into making sure the event was fully accessible. It was a fun day, and everyone got a chance to take part.

What does person-centred support mean?

What people at the Get Together day thought about person-centred support.

Everyone thought person-centred support meant service users are at the centre of services. Eight important things were picked out. This summary tells you about them.

Choice and control

Service users think person-centred support has a lot to do with choice and control:

- being in charge of your life;

- being able to change your support if it does not work out for you;

- having support to make decisions;

- having the chance to learn about making decisions.

Setting goals

This means deciding what you want to do or change in your life. Some managers and staff were worried that service users would get upset if goals did not work out, but some service users thought this was an excuse that stopped them from trying to make changes happen.

The importance of relationships

Everyone thought that relationships between service users, staff and managers were very important. Also, networks are important, so that people know they are not alone.

Listening

Service users said that good listening is very important for person-centred support. They gave examples of when their views had not been listened to or when other people thought they knew better.

Information

Everyone thought that good, accessible information was very important. It is difficult to make good choices without it.

A positive approach

Staff and service users said that a positive approach was really important. Being positive helps service users feel more confident and good about themselves and so make better choices.

Learning

Person-centred support helps service users try new things and learn new skills.

Flexibility

Person-centred support is about being flexible to suit one person's life.

What are the barriers to person-centred support?

What stops service users getting person-centred support?

People at the Get Together day talked about things that make it difficult for service users to get person-centred support. This summary tells you about these important things.

People think they know what you want

Sometimes staff think they know what service users need, but they are not always right. This can make it difficult for services users to get their voices heard.

Inflexibility

Sometimes service users have to fit themselves into the service and the way in which it is organised, not the other way round. Services do not change because 'we've always done it like this'.

Lack of information

Service users need good information about their options to be able to make good choices. Staff may not have the information they need to help service users make good choices.

Money and resources

A lack of money and resources may stop people getting person-centred support. But some people thought money was wasted or used as an excuse. Service users thought managers could be better at planning and buying the support people want.

Local authority charging policies

Local authorities ask service users to pay something for their support. People thought this cost could stop people from asking for a service or make people ask for less than they need because they are worried about the charge.
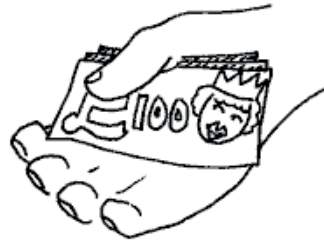
Staff time and approach

Some people said there is not enough staff time or good quality support to get person-centred services. This makes building good relationships and making plans more difficult. But staff attitudes and lack of training are also important.
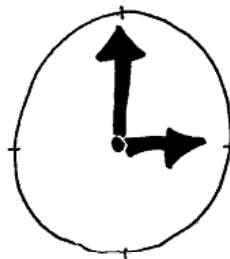
Risk and regulations

Many managers and staff talked about a clash between 'keeping people safe' and person-centred support. Too many risk assessments can be an excuse not to do person-centred support. This difficulty was very real for staff working in mental health services.

Communication

People said that communication was often not good between different agencies, and this made person-centred support difficult.

Culture and language

It can be difficult for some service users from black and minority ethnic communities to get person-centred support. Good interpretation and information is needed. Some local authorities are confused about whether to set up separate services for a particular minority ethnic community or to make all services open to everyone.
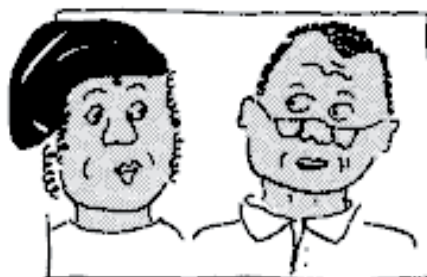
Institutionalisation

This means when service users live a long time in a service and get so used to the way things are done that they find it hard to change. The same thing can happen to staff. People become scared to break habits and move on. Service users may need a lot of support before they can start thinking about different choices for living.

Negative experiences of user involvement

Some service users spend a lot of time going to meetings and giving their views to help services become better. But they can feel very frustrated when services do not change. User involvement is a problem when:

- people are not supported to get involved;

- people are not given feedback about what happens next;

- nothing seems to change afterwards.

Outcome measurement

It can be hard to count the exact things that change after good person-centred support. But organisations like to have facts about what changes. They often have to report back about things the government says they should do. Sometimes services are set up so they fit government targets, rather than being really person-centred.
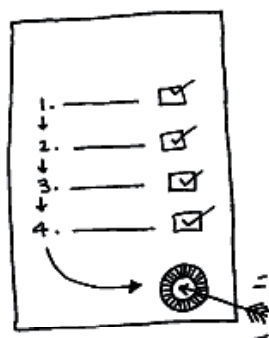
Eligibility for support

Local authorities have very tight rules about who can get a service. These rules are called 'eligibility criteria'. People who need support often have to show how *little* they can do to get a service, rather than what will help them live full lives.

Family carers

Person-centred support is about helping individuals make choices and get the support they want. Staff also need to work with families and friends to help them get over their fears about risks and really see what people can achieve.

Geographical inequality

People at the Get Together event said that what sort of support you get depends on where you live, not just your needs. Things are not equal in every area.

Transport

Problems with transport can be very important, especially for people living in rural areas where services and community help may be far away and there might be little accessible transport.

Individualism

This means that sometimes people think 'person-centred' means the person alone, without their networks. Person-centred support is about matching support to the individual so people achieve their full potential. 'Individual' does not have to mean 'alone'. Person-centred support is about service users having a range of options to choose from and being able to make changes as life changes over time.

Ageism

This means the way society is unfair towards people just because of their age. Many people at the Get Together event thought that services for older people were less person-centred than for other people.

How can we overcome barriers?

People's ideas for getting over the difficulties in making person-centred support happen.

Participation

Service users need to be involved in services as individuals and together in groups for change to happen. Good accessible information is needed for people to get involved. Getting together with other service users also helps. People at the Get Together said that service users should get involved in planning, running and offering services, and in working out how well they are doing.

Improving consultation and involvement

Everyone at the Get Together thought that service users should be more involved in services. To make this happen people need:

- lots of time and information before meetings to prepare;

- accessible places for meetings;

- support during meetings;

- not to be the only service user present;

- to include those facing lots of barriers.

Trust

Many staff members and managers spoke about the importance of trust between services and service users. This helps people feel more confident and makes better relationships.

Relationships

Good relationships between all the people and agencies involved help service users take positive risks for change.
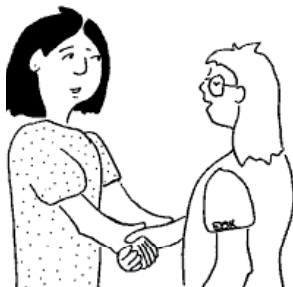
A positive approach

People at the Get Together felt that service users become more powerful and confident by getting involved.

Advancing good practice

This means making what staff do get better and better. People thought that sharing ideas about good practice in person-centred support is very important.

Promoting person-centred support

People thought that person-centred support should be advertised and talked about in a more organised way so that more people get to know about it.

Information

People thought that good accessible information is a very important part of person-centred services and support.

Training

People thought that service users and their groups need more training and guidance to become confident and assertive about services.

Direct payments

Direct payments can be a way for service users to control their support, but only a small number of service users get one.
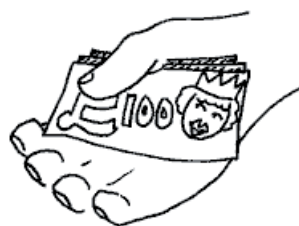
Service users working together

Service users said it was easier to speak up and have a say when you have the support of a group.

Support and building confidence

People need confidence to get involved and to make the best of person-centred support. Confidence can grow through training, advocacy and service users supporting each other.

Small steps

What seem to be the small steps that people make towards their goals are very important.

Core values

Many people said that person-centred support is about a way of thinking and acting about people and services. These are the core values of a service. For person-centred support to work, services may have to change in deep ways.
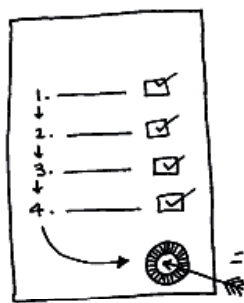
Person-centred support is not another thing services have to do, it's what they *must* do. It's not another job – it's *the* job.

Discussion and recommendations

The main things that this report talks about and what the Standards We Expect project thinks should happen next.

These are the main things that this report talks about:

- The Get Together day brought together service users, staff and managers. All three points of view are important to make person-centred support happen.

- There was a lot of agreement about what person-centred support is, what the difficulties are and how we can get over the difficulties.

- People enjoyed being together. There needs to be more chances for people to get together to talk about person-centred support.

- People think person-centred support is a good thing. Even though there are difficulties, people feel positive about it. We do not have to wait for big changes to make it happen. We can do it now.

- Some of the difficulties in doing person-centred support have been talked about a lot, such as not having enough money or time. But other difficulties are more complicated.

- Core values about person-centred support are very important. Core values are the important beliefs and attitudes each of us holds.
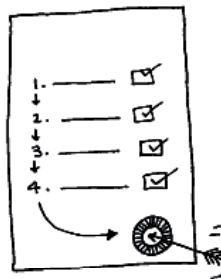
- There are no short-cuts to doing person-centred support right.

- Person-centred support is not just about PCP. This is just one way of doing it.

- *How* we work together (the 'process') to do person-centred support is just as important as what we're aiming for (the 'outcomes').
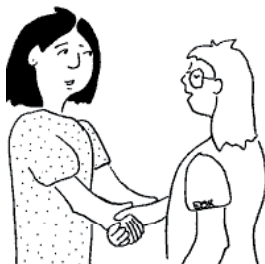
- Service users said that being involved in decisions about services is very important. User-controlled organisations are very important for person-centred support.

Ten important things

The Standards We Expect project makes a list of ten things that should happen to make person-centred support better.
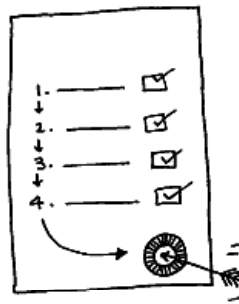
These ten things are:

1   Service users, staff and managers must all be included in work and talk about person-centred support.

2   It does not help person-centred support if we only list success by numbers and prices. People need the chance to talk about good changes in other ways.

3   Any research or study about person-centred support must include the views of service users and staff.

4 There are lots of ways to do person-centred support. We need to study them to work out what is good or bad about each.

5 Information about person-centred support must be accessible for everyone.

6 Carers need support so that they are positive about person-centred support. This needs more work.

7 Service users, staff and managers like meeting together to share ideas and experiences. There should be more of this.

8 There should be more study about new ways of doing self-directed support (such as individual budgets). What is found out should be shared with service users in accessible ways.

9 Services that are run and controlled by service users might be very good for person-centred support because service users trust them.

10 Worries about 'risk' are getting in the way of person-centred support. This needs to be looked at.

What happens next?

The Standards We Expect project is doing three main things in the second year of the project:

- individual work in the project sites;

- training for service users, staff and managers in the project sites;

- another Get Together event in autumn 2007.

Introduction

This report brings together for the first time the views of a wide range of service users, face-to-face practitioners and managers about a key new concern in public services, particularly in personal social services. This is the desire to increase the choice and control such services offer people and to move from traditional approaches where service users were expected to fit into services to new ideas of 'person-centred support and personalisation'. Here, the aim is for provision to be shaped by people's own rights and needs.

Person-centred support

There has been a new emphasis in recent years on developing 'needs'-led support and services for disabled people, mental health service users, people with learning difficulties, older people and other groups of long-term health and social care service users. The aim has been to move away from longstanding institutional and service-based approaches to providing support. Far-reaching changes have been taking place in thinking, policy and practice about personal social services and social care; about who should provide support, how it should be provided and who pays for it.

There has been a widespread reaction against people being slotted into separate services rather than services matching their rights and needs and enabling them to live in mainstream society. There has been a growing concern that service users themselves should be at the heart of the development of policy and provision. Ideas of partnership, participation and empowerment have become central in social care discussions and developments.

Meanwhile service users have developed their own organisations and movements – locally, nationally and internationally. They have developed new ideas and philosophies, such as the social model of disability, which highlights the broader barriers that disabled people face, and independent living, which frames the provision of support in terms of enabling people to live their lives on as equal terms as possible, rather than it being seen as a measure of their dependence or incapacity. Service users and their organisations have inspired new policies based on such thinking, such as direct payments and user-led services, which aim to put people in control of the support they require.

The term 'person-centred support' has emerged as a new umbrella term to cover a wide range of new developments and approaches, from 'person-centred planning' to direct payments, concerned with putting service users at the centre of policy and practice to ensure that the support they receive is shaped primarily by their individual and collective rights and needs, hopes and goals.

Most recently, another important development has also emerged as part of this philosophy. This is becoming known as part of the 'personalisation' agenda and is concerned with matching public policy with the individual requirements of each person. In social care, this is being called 'self-directed support, 'individualised support' or 'individual budgets'. The aim here is to put people in charge of a range of funding streams which can be used to purchase the services and support that they want in order to live their lives to the full.

So far there have been only a limited number of pilot projects taking forward 'individualised budgets', but they have captured the imagination of policy-makers. Government has expressed a strong commitment to such approaches to person-centred support, for them to become a central plank of social care, and there also seems to be wider cross-party support for them. As yet, the evidence base for individualised budgets is limited. Nonetheless the government has committed itself to achieve 'personalisation' in social care by 2011.

Yet, despite the growing interest in person-centred approaches to support, they still seem to be marginalised and only appear to be being implemented on a limited scale. For example, little more than 50,000 service users currently receive direct payments, while 500,000 people, largely older people, are still living in residential institutions. Social care policy and practice have a key role to play in enabling service users to live on equal terms with others. However, UK social care has a history of frequent restructuring and reorganisation which has still not resulted in appropriate support being available for all service users systematically, reliably and equitably, addressing their rights, needs and difference.

The Standards We Expect project

For these reasons, it is likely to be particularly helpful now to find out more about person-centred support; what it means, what it can offer, obstacles in its way and how these might be overcome. These are the essential aims of the Standards We Expect project, which is concerned both with finding out more about person-centred support and helping to take it forward. The Standards We Expect project is a three-year research and development project supported by the Joseph Rowntree Foundation in 2006 as a key part of the work of its Independent Living Programme.

The project is being undertaken by working closely with eight partner sites as well as linking and exchanging information with a wider network of twelve interested agencies. The project is service-user led and is being undertaken by a consortium of organisations. These are Shaping Our Lives, the national service-user-controlled organisation and network, Values Into Action, the Centre for Social Action at De Montfort University and the Centre for Citizen Participation at Brunel University. Individuals involved include members of the Race Equality Foundation, social work practitioners/researchers and a consultant experienced in working with older people.

The project aims to encourage and guide the development of person-centred support among the eight service provider partner sites, but also to support information exchange within the wider network and more generally. To this end, the project has established its own website.

There are four key elements to the way that the project is being undertaken.

1   It has been designed to ensure that the key, but often marginalised, perspectives of service users and current face-to-face practitioners are centrally involved, alongside those of managers.

2   The project is participatory in approach. It aims to involve partners, particularly service users and practitioners, as fully as possible and seeks to ensure that they are fully involved in processes of change in their own local partner organisations and service providers.

3   It is being undertaken with the underlying belief that, if real change is to take place, it will have to be owned by the key stakeholders involved – and that these must include service users and practitioners. Thus their views about key issues are seen as central.

4   The project focuses particularly on three key issues:
    –   What does 'person-centred support' really mean?
    –   What are the main barriers to such person-centred support?
    –   How can these barriers be overcome?

5   The project particularly engaged and sought to explore the views of three groups of stakeholders:
    –   service users;
    –   face-to-face practitioners working with them;
    –   managers and others with key roles in the provision and purchase of services.

This report

This report provides the first findings from the project. The findings reflect the project's overall process and priorities. They bring together the views of a wide range of service users, practitioners and managers about the three key issues identified as the focus for the work. These are drawn from a Get Together day which was organised as a key element in engaging people in the project. This Get Together day brought together in equal numbers a total of more than 60 service users, practitioners and managers from the overall network of 20 partners involved in the project in November 2006.

The aim was to find out what members of these key constituencies had to say about the three key issues being explored in the project as a basis for the development work that will be undertaken over the rest of the project's life. A strong emphasis was placed on ensuring that the event was fully accessible to all participants and that they were able to contribute their views in effective and comfortable ways. A similar stress was also laid on people being able to hear from, and exchange and share experiences with people involved in other sites.

The structure of the report

The report is organised in five main chapters. The first describes the event whose findings we report here. The second explores what person-centred support meant to service users, practitioners and managers who took part. The third focuses on the barriers they identified in the way of person-centred support, while the fourth chapter contains their ideas about how such barriers might be overcome. A final chapter identifies some initial conclusions from what people have to say about person-centred support as well as setting out the implications for further work.

A series of appendices provide the reader with additional information. Appendix 1 provides a brief description of the Standards We Expect project. Appendix 2 provides the programme from the Get Together day. Appendix 3 reproduces the feedback form for the Get Together day. Appendix 4 offers a resource list of relevant agencies and organisations as well as helpful publications.

1 Getting people together: sharing views

The Standards We Expect project works closely with eight partner sites and has developed a broader network of twelve additional sites. The aim of this report is to share the views and experiences about person-centred support of key stakeholders from all 20 partners. A key aim of the project has been to share learning and experience about such person-centred support. While there is increasing interest in person-centred support, most people involved seem to have limited opportunities to talk about it, particularly outside their own organisations and services.

The 20 partner sites involved in this project represent a very wide range of services and agencies. Eight core areas or sites form the basis for the project's research and development work. The project is working individually with them, tailoring its work to support their particular situation and goals for change to achieve more person-centred support. Other outputs from this project will report the findings from this work.

The projects

The 20 participating sites include a wide variety of partnerships and services.

- They range geographically from the north of Scotland to the south-west of England. They include urban, metropolitan and rural areas.

- They include partners from the statutory, independent and voluntary sectors (and some include agencies from more than one sector). They include health and local authority organisations, but not directly any user-controlled ones.

- The kind of service they provide ranges from residential and day provision, to specific community-based services: for example, support with employment, housing and information technology. They include day services, respite care, outreach and development work, advocacy, advice and social work support. They include black and ethnic minority as well as mainstream organisations and groups.

- They vary in scale from a single residential unit for ten people to a network of providers working with hundreds of service users, from large-scale psychiatric provision to supported housing.

- Their history and approach towards person-centred support is varied. Some of the partners see themselves as at the forefront of innovation and the implementation of person-centred support. Others are seeking to overcome particular challenges or to modernise their approach.

The partners applied to the Joseph Rowntree Foundation to become part of the project. All expressed an interest in making their services more person-centred.

The service users

When we use the term service users we mean people who receive or are eligible to receive health, social care and welfare services. This can be on a voluntary or compulsory basis. We particularly take it to include people with long-term experience of such services. This can include a very wide range of groups and, indeed, does so in this project.

Peter Beresford speaking at the Get Together event

The sites involved in the project provide services for and include a particularly wide range of service users. This extends to people with physical or sensory impairments, people with learning difficulties, people with dementia, mental health service users, older people, people using end of life care services, people who have substance misuse problems and homeless people, young single mothers, people leaving prison and people under section in psychiatric services.

Some service user groups repeatedly emerge as facing particular barriers in their lives and in the way of being adequately involved in developing the support that they want. These include:

• black, Asian and minority ethnic service users;

• people who communicate differently;

• people with learning difficulties seen as having 'profound and multiple impairments' and/or 'challenging behaviour';

• older people, including very old people;

• people living in residential institutions or restricted to their own homes (Branfield *et al.*, 2005; Branfield and Beresford, 2006).

This project includes all these groups.

Involving people in change

The move to person-centred support represents a major change in philosophy, approach and practice in support services. This project has been based on a philosophy of enabling key stakeholders to be engaged in this process of change. For such change to be meaningful for service users, for it to be owned by, rather than imposed upon them and to ensure that it serves its intended purpose, it seems essential that service users are fully and equally involved.

The project has also prioritised the involvement of face-to-face practitioners. This includes both professionally qualified workers and the low paid and often unqualified workers (including a preponderance of women and black and minority ethnic staff) who make up the greater part of the social care workforce.

Previous experience has shown that attempts to bring about major change in embedded service cultures and established institutional practices face almost insurmountable obstacles without the support of face-to-face staff. Research has shown how resettlement from the mental handicap hospitals, for example, was systematically impeded and even sabotaged by staff who felt alienated, rejected and abandoned by the policy (Collins, 1992, 1993; Fitzgerald, 1998). More recent research into the modernisation of day services for people with learning difficulties (Dowson, 1998) and into obstacles in the way of direct payments (Henderson and Bewley, 2000) have produced similar findings.

There is also considerable evidence that face-to-face staff in social services departments are experiencing low morale (Balloch, *et al.,* 1999; Lymbery, 2001; Postle, 2001), resulting in poor recruitment and retention rates which, inevitably, has knock-on effects for the people with whom they work and their ability to consider and implement change and innovation. By enabling staff to share ownership of the aims, ideas and methodologies, we shall more readily obtain their goodwill and support.

In the project, we saw extending ownership to service users and practitioners as key to developing good practice. They provide key knowledge bases for improvement as well as a force for change. We do not believe that either a 'bottom-up' or a 'top-down' approach on its own is sufficient, but rather that both approaches need to be used simultaneously.

The first phase of the project was exploring and identifying with service users, face-to-face practitioners and managers in each of the eight sites their views about:

- what 'person-centred support' really means;

- what the main barriers to such person-centred support are;

- how these barriers can be overcome.

This was done by holding meetings with service users, face-to-face staff and managers in the eight sites. In these meetings, we also worked with these groups of people to identify the key issues in relation to person-centred support in each site.

The next key task, however, has been to exchange and share such views and experience both between the three different stakeholders and between all the 20 sites. In this way, hopefully it becomes possible to synthesise the views of different stakeholders from a wide range of agencies and services, negotiating different perspectives, sharing different experiences. What was needed was an effective means of doing this which would be as accessible and inclusive as possible and which would provide a realistic opportunity of engaging as wide a range of participants as possible to enable people to form, share and explore their collective views.

The Get Together event

The most practical, inclusive and accessible way that we could think of to do this was to organise a 'Get Together event'. In this way, we could bring people together, try to ensure that they had a good day out and share and develop the learning from the project. An essential aim of this project was to enable stakeholders to engage in the process of change both through identifying existing forums and also through exploring new ones. The Get Together day represents just such a new forum.

The Get Together day was an important stage in the project and represented the first opportunity for participants from each project partner to meet together. It provided an opportunity:

- for people to get to know each other and network together;

- to share experiences and discuss good practice;

- to learn from each other;

- to find out more about person-centred support;

- to get new ideas about overcoming barriers to person-centred support;

- to take forward discussion which could stimulate participants and renew their interest in person-centred support;

- for the project to gather data and work out next steps with participants.

Aiming for inclusion

To try to ensure that the Get Together was as inclusive as possible and to make sure that it could involve the widest range of participants as possible on as equal terms as possible, we placed a particular emphasis in how we organised it on *access* and *process*.

Access

We worked hard and built on a lot of experience to make the day as accessible as possible for everyone involved in the project, particularly service users. The venue was chosen with access for disabled people closely in mind and the need for plenty of space to create a relaxed atmosphere. Separate breakout rooms were used for

discussion groups to create a supportive and confidential environment. We set aside a quiet room that could be used for silent relaxation, contemplation or prayer.

Information about the day was circulated well in advance (8 weeks prior to the event). A detailed access requirements form was circulated to assist planning. This covered a wide range of topics, from dietary requirements and preferred method of communication to the type of seating people required. The project encouraged participants to contact us in order to ensure that access needs could be accommodated and to reassure them that their attendance was valued.

'Roving' personal assistants were also available to assist in any way that participants required. A speech-to-text transcriber was used in the plenary session. A loop system was available for hearing-aid users. The agenda and background information were circulated in advance to meet all access needs. Large print versions and versions in community languages were made available. Documents were written in plain English and with the addition of pictures/symbols to improve access for people with learning difficulties.

When introducing the day and the small group discussions, we took care to use plain English. There is a lot of jargon in this field. 'Person-centred support' itself can be seen to be a jargon term. In order to include fully those who had not previously heard the term, the leaders of discussion groups asked questions that were intended to encourage participation, based on participants' experience of services. They tried to encourage discussion about the features of good and bad services and how responsive they are to the needs of individual service users.

Process

The process of the event was also designed to enable maximum participation for all involved. The programme was based on this aim. So, for example, we made sure that the day was not too long, in order to encourage participation from people who might find a longer day difficult or who were travelling long distances. We paid travelling expenses, which included overnight accommodation for those who could not travel in a single day or who needed to rest in order to be at their best. The programme was designed to offer plenty of breaks as well as a variety of sessions. There was a mixture of small groups and larger, plenary sessions. The day began with a short and lively breaking-the-ice session. After lunch, there was a short entertainment slot to reinvigorate participants, performed by a singer and performance poet who is also a service user.

The event was held in a light and pleasant location, and we made sure that good quality refreshments were provided (which met any specified dietary requirements), in line with our commitment to a high-quality occasion which signified our valuing of and respect for participants.

As well as the opportunity to make individual contributions in discussion groups and plenary sessions, we also offered people the chance to make contributions on post-it notes in our networking area and via our 'video room', where people could contribute either alone or in pairs. In this way, it was possible for people to contribute in the way that they felt most comfortable.

We used a system of colours and shapes to denote membership of discussion groups and to signpost people to the correct rooms. These symbols were included on the name badges that all participants were given when they registered for the day.

Overall, we ended up with a very even mix of participants as intended, of around 20 managers, 20 face-to-face workers and 20 service users taking part in the Get Together day. (For further information about the Get Together day, see Appendices 2 and 3.)

Exploring different perspectives

We focus in this project and in this report on the views of three particular groups of stakeholders:

• service users;

• face-to-face practitioners;

• managers.

In undertaking the part of the project that we are reporting here, we encountered a significant degree of consistency in the views and concerns of participants from these different groups about person-centred support. There were also differences of view and emphasis. In each of the three following chapters reporting the findings in more detail, we look at the similarities and differences in views and comments from the different groups.

Choice of terminology

At this point it may be helpful to explain why, in undertaking this project, we adopted the term 'person-centred support'. Health and social care are fields with more than their fair share of jargon and specialist language. We did not want to add to this. At the same time, we wanted, in as straightforward a way as possible, to delineate to participants the general focus of our interest and the work we were doing. We chose 'person-centred support' rather than other alternatives such as 'person-centred planning', 'person-centred care' or 'personalisation', because it did not have specific associations, include any devalued words or carry any particular baggage of its own.

As can be seen from the discussion above, we are interested in a wide range of services and did not want to limit the focus of our project to some particular individual approach. The term person-centred planning (PCP) is relatively well established and defined. Its background lies in work with people with learning difficulties. It is associated in many people's minds solely with that client group. Furthermore, it is focused on various planning techniques (Essential Life Planning, MAPs or PATH). While some of the stakeholders at our project partner sites have been trained in one or more of these techniques, many more have not. Also, we were not only interested in PCP and had no specific commitment to it, although we do see it as one expression of person-centred support. We do not use the term 'person-centred care', as it is both too narrow in its scope, and because it is not consistent with the social model of disability. Many service users dislike or reject the concept of 'care'.

We wanted to employ a term in the project that could readily cover the whole range of services, from personal assistance for disabled people to services working with people with addiction problems and which could also apply to all groups of service users. We wanted to base our work on a straightforward descriptive term, rather than one which was associated with a specific approach or set of values. Person-centred support could equally include PCP or direct payments or indeed other self-directed support schemes. That was why we decided to use it.

2 What does person-centred support mean?

> One question which care planners should ask themselves is 'What would I want, if this was my own situation?' (Service user)

Person-centred support is the key concept for this discussion. Participants came from a wide range of backgrounds, not least with respect to the services that they were using or had been involved in providing. They also included a diverse range of service users, from older people to young disabled people. Some people had very clear ideas about what was meant by the term person-centred support, while others had not heard it before. So a starting point for the way in which discussion was organised was to make things clear, without pre-empting people's own ideas and definitions.

A number of themes relating to how people defined person-centred support emerged during the day. These were expressed during the different opportunities that took place for discussion during the day, in large and smaller groups. They are the focus of this chapter and provide a working definition from people's different perspectives as service users, face-to-face practitioners and managers that informs this overall report.

Putting the person rather than the service at the centre

The most frequently identified characteristic of person-centred support was putting the person rather than the service at the centre of the process. There was a strong consistency between different stakeholders about this. For service users it meant:

> being at the centre of your service;

> start with the person not the service.

Face-to-face workers said:

> The client should be the central person, by setting up a plan, looking at where they are now, their journey, dream and goals.

> We try and tailor our services around what they want rather than say, 'Look, this is it'.

> Fitting the service around the service user instead of the other way round.

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Managers said:

> We need to tailor our services around what users want and provide consistency of care as well.

> Focus around the individual rather than the statutory services we have in place.

Their comments suggest a contrast between person-centred support and 'service-led provision'. A 'one-size-fits-all' approach was not what people wanted and was seen as inadequate. Person-centred support demands an individual response and a commitment from services and workers to take account of individual differences and to respond flexibly. Thus:

> Develop services around that, focus around the individual rather than the statutory services we have in place. Rather than fit those people into particular boxes. (Manager)

Choice and control for service users

Choice and control were widely viewed as being key to defining person-centred support. Support was seen as a vehicle – a means of ensuring choice and control for

the individual service user. Service users sometimes explicitly used these words to say what person-centred support meant for them.

> Giving me choice and control, putting me first.

> Having control so that when things aren't working for you, you can say so.

They also explained what they meant by the words:

> Letting me choose and speak. Remember – I have the right to choose what I do and when!

> Being able to decide for yourself what you want to do and not letting anyone decide for you. Other people may have good intentions for what you need but you might know better how to achieve it.

> [Service users] are viewed as something to be done to or at and for me it is about, I am in control of my life now and no matter how disabled I become, I still want to be in control of my life. For me it is about my control and that is how we will get person-centred care because I will be in charge of it not somebody else.

This principle of self-determination ran through service user's responses about person-centred support. They highlighted people's desire to be able to make choices and to change things if they changed their mind or things weren't working out.

> Your worker can't tell you what you need, you know what you need.

> At the end of the day he provides a service, you are part of his service and you have got to get some sort of understanding there that that works out because if it is not then you will get into a situation where he will be doing what he wants to do and you will be doing what he wants to do and that never works.

Face-to-face workers and managers also identified choice and control as important in person-centred support.

> So I think part of it is about having that control just to say, that is not working for me and I don't want to do it anymore and I won't do it anymore.

> Our clients, if they have individual support plans as well as the person-centred plan, it is very much client led so if they want to spend their hour a week going shopping then that is what we do. If they want to go for a walk in the park then that is what we do. It is very much led by them.

> Giving people choices and a means to do that.

Some workers and managers, however, added to this the importance of supporting service users in their decision-making. What they made clear was that, for people who had significantly been denied choice and control in their life and had limited experience of either, just offering it was not necessarily meaningful or enough. Some workers reported problems they had experienced when service users found it difficult to express themselves.

> If you are able to ask them a question and they have to give a choice of an answer, you are straightaway starting them on the route to empowerment.

> So you bring them together and then you say, have I got this correct? This is what you want? And getting them to agree or say 'no that is not what I want', and adjusting to what they are wanting. And then you go with that and then adapt it. That is how I have kind of done my little bit, I always come back with, 'is this what you want?' because I am not planning [for them], I am just there to be [helpful].

> Giving the person the choice, but the person has to want to make the choice.

Service users made the same point about needing to gain skills to make real use of choice and control:

> I still have that freedom and I am more able to do it, at first I wasn't so independent, but now I am, I have mates I go out with on a Friday night.

This difficulty should be seen in the context of barriers to person-centred support identified in the next chapter of this report, such as institutionalisation and a lack of information.

Choice and control were contrasted with more paternalistic approaches to service provision where service users might be passive recipients of services and assumptions that the 'service knows best'. As one worker said, it is

Actually allowing people to make the choices and the decisions rather than doing it for them.

Setting goals

Most people agreed that a key part of providing person-centred support is the identification of goals and aspirations with service users.

> It is about saying what your dream is. So that everyone can have a dream. And it could be to be an astronaut or to live in a mansion or whatever, but then you go back and you start to, step by step, see what the blocks are to you getting that and step by step what you can do in order to begin to achieve that goal. (Face-to-face worker)

The setting of goals does not merely establish an end point or target to work towards. Person-centred planning, a well-established approach to person-centred support, has a focus on the process of taking steps toward overall goals. Goals may be things that are achievable in a relatively short period of time and involve only a small number of steps. Alternatively, they may be on a larger scale and consequently prove more complex, taking longer to realise. A key aspect of the process is the relationships formed by the service user with those who are involved in planning.

Many managers and front-line workers expressed concerns about services not being able to support service users to reach particular goals, especially if these were seen as too ambitious or 'unrealistic'. However, other workers believed that service users have realistic aspirations and 'don't want the moon and the stars'. The setting of goals would offer a reality check on whether they could be achieved so as not to set someone up to fail.

> But everybody is allowed to have dreams and higher expectations and to aim towards them, but they are ultimately not going to get to the moon or the stars or whatever it might be. We all have dreams so why shouldn't everybody have them?

There was some debate about whether service users should set 'small' or 'big' goals. One manager said:

> Wish-lists developed with users aren't constructive. Planning should begin with more achievable things.

This discussion about goals demonstrated that participants had both a wide cross-section of views and a range of experience and backgrounds. Furthermore, it was apparent that some people had been trained in particular methods of person-centred planning (such as Essential Life Planning), while others approached the subject from a point of view of experiencing services first hand.

Some of the comments suggested that services feel a responsibility to meet all the things service users identify as goals. This may lead them to approach the subject with a negative attitude in order to avoid future disappointment. One person referred to this as 'gate-keeping'. However discouraging people from setting ambitious goals has serious implications, because it may reinforce negative stereotypes and undermine service users' self-esteem. Ironically, it may have the very opposite effect to that intended by person-centred support – that is to say it may further disempower people rather than provide a structure that supports the development of independence and integration. Thus, while the setting of goals is seen as key to person-centred support, it can also raise complex issues for all stakeholders.

> Question: Does person-centred support mean getting everything you want?

> No, I think it is getting what is necessary. Some people can turn around and say they want this, that and the other and expect to get it, but I don't, I expect to get what people need and that's it. (Service user)

No it doesn't, because none of us get exactly what we want, but I don't think there is any harm in having a dream no matter how unrealistic that dream is because the process that is really important is the journey you take towards that dream. At any time that dream can change but just having one out there and taking the risks and going through the experience of trying to achieve it is what is really important. (Face-to-face worker)

We shouldn't forget that if somebody does ask to go to the moon there are feelings behind it, and we need to ask that little bit more, what is behind them wanting to do that. (Manager)

The importance of relationships

Service users and face-to-face workers in particular identified the importance of the *relationship* between an individual service user and their key worker or planner for person-centred support. There was a widely held feeling that time and effort must be invested in forming a relationship before person-centred support can be made real. One worker said:

It was all about meeting our clients, building a relationship is the real foundation.

Others said:

> Communication is important. You need time to get to know service users.

> It is building that relationship that makes the person-centred bit follow on.

The feeling was that, without this foundation of knowledge about a service user, their likes and dislikes, character and personality, a service cannot begin to be person-centred.

> Then the greatest thing that happens is you get this empathy and when that happens there just seems to be a natural progression, there seems to be that, what [person's name] was saying, that greater understanding because although there needs to be the education side of it, it seems to fall more into place once you share it with somebody who knows what you are talking about and it doesn't seem to matter where they come from or what colour their skin is. (Face-to-face worker)

> You need to develop the relationship before you can start planning. (Face-to-face worker)

> Definitely it is about clarity and transparency and honesty upfront about what about the choices are. (Manager)

There was a strong sense among participants that building relationships is a central element of making services person-centred. Person-centred planning techniques inherently place great importance on building and maintaining networks. There was a shared belief that forming relationships is one of the most important benefits associated with such planning. Some people made the point that forming a group of people to assist with a person-centred plan creates a sense of community and solidarity that can be otherwise lacking in the lives of some service users. This can reduce feelings of social exclusion.

Listening

Participants emphasised the importance of *listening*. Many service users highlighted this, contrasting bad experiences of services where their views had not been listened to or they were dominated by people who thought they knew better. Service users made it clear that they should be asked their opinions and listened to.

Listening, *really* listening.

Respect that they are the expert of their own lives and their own needs.

So we are not forgotten.

We just don't get no help whatsoever and we feel we need it. I feel if someone was to come around and see us and talk and ask exactly what we need, even if they couldn't provide it, at least it would show us that someone is caring and listening to us.

Face-to-face workers similarly said:

Involving everyone together, talking and listening.

They highlighted what underpinned this conclusion.

I think that first of all the real belief that the expert in the room is the person, the client, and respecting that. They are the expert of what their needs are.

When we did some work with her on person-centred planning, and she actually started to be more expressive about what she wanted to do and more about positive stuff, she ended up saying, I hate going to the gym, I want to play chess and scrabble because that is what I am really interested in, can you help me to get involved in that.

Because we are just learning that as a support service provider that you have to understand that still you will need to learn from the service users.

Face-to-face workers expressed a view that planning meetings are most effective when participants meet on an equal basis, with everyone's thoughts and feelings being respected. Revealingly, one worker reflecting on the challenges of person-centred support, emphasised that their work was often targeted at overcoming some very basic barriers. The importance of listening was at the heart of this.

It is about goals but you have got to find an achievable goal … a lot of our work is trying to get social workers to understand that they need to listen to what people want. (Face-to-face worker).

Information

Running through the discussions, there was agreement about the central role played by accessible, relevant and reliable information for service users. Many people spoke of personal experiences of not knowing what services were available to them and the difficulties this created. A powerful message emerged that meaningful choice is not possible without an understanding of what is possible. Information is key for this. One service user said:

> You need the right information to help you choose. It must be informed choice.

A manager said that a person-centred approach has to include:

> Adequate knowledge on specialised topics (those specific to the service user).

One example given related to people who had experienced head injuries. The manager involved said that in order to provide support effectively to an individual service user, the service must have background knowledge and information about what that means. A service user said:

> I go to Headway and I have been trying to get an extra day because I only have one a week. I have been finding it so good in terms of getting right to the point of where I am at with my problems. I go to another centre but I might just sit there sometimes. I am not being disrespectful to the place but they can't offer me the same.

A positive approach

Some participants felt very strongly that a person-centred approach must value people and focus on the positive. Service users said:

> [Highlight] positive abilities, not the negatives.

> Giving the person the opportunity to achieve.

> By believing in people's value and giving all people a chance.

A manager expressed the issue in a very similar way:

> Actually building on the good bits rather than focusing on the needs.

This positive approach has an impact on people's self-esteem and self-belief. Face-to-face workers summarised this in comments they made:

> I think the by-product or even the actual point of [person-centred support], is to raise people's self esteem and awareness and I think confidence building is paramount if people want to change their lives and be master of their own lives. In our organisation we are increasingly giving people, or enabling people, to make choices for themselves and consequently some people are really beginning to believe in themselves and being able to feel as though they can integrate into mainstream society, and indeed make a contribution. (Face-to-face worker)

> They (service users) have also got great things to offer and it is about finding those and actually saying, 'hey you are a worthwhile person to contribute something', rather than just receiving services all the time. (Face-to-face worker)

> They have skills, they have experience. Most of them have a wealth of knowledge, and it is often that if you can actually channel some of that skills enabling the person to do something, making a positive contribution. (Face-to-face worker)

One face-to-face worker also made the point that working in such a valuing and positive way had positive effects more generally:

> [it] actually makes life for everybody so much more enjoyable and easier.

Learning

A number of participants spoke about the importance of learning to person-centred support. They said that service users should be supported to try new experiences and learn through these. As one service user said:

> When it doesn't work for you, try something else.

This learning can be viewed in the context of life experience and towards the development of independent living skills.

Flexibility

Flexibility emerged as central to person-centred support. One person who made this point was referring to services that can respond to individual needs and adapt to personal choices. Flexibility implies the service's ability to adapt as people's needs change or they decide to pursue different goals. One service user said that being person-centred means:

> Remembering everyone is different and has different needs.

This was a point which a manager also took up:

> So person-centred care has got to be flexible and rapid.

Differences in perspective

There was considerable agreement over the meaning of self-defined support between service users, practitioners and managers.

All three constituencies agreed about the importance of:

- putting the person at the centre of the service;

- relationships;

- the provision of information.

Service users particularly emphasised the importance of choice and control over the service they received. All three groups agreed about setting goals, but some workers and managers voiced concerns about raising expectations that might be difficult to meet when setting goals. Workers identified having a positive approach as important.

3 What are the barriers to person-centred support?

Having established what people understood by the term 'person-centred support', the next issue we wanted to explore with them was what they saw as the *barriers* to such person-centred support. Participants identified a large number of barriers. These could be big or small barriers; barriers which could be seen as long or short term, local or national, relating to broader structural issues or more personal and psychological in origin. Some of the barriers people identified could be seen as relatively minor matters that could readily be put right. Others were much more fundamental and likely to be common across many settings. They could be seen to suggest a number of principles for effective person-centred support.

A number of themes relating to barriers emerged. Wherever possible, we have grouped together comments relating to these. Some of these themes specifically relate to characteristics which people associated with person-centred support and which we identified in the last chapter. Others can be seen as barriers that may apply to accessing services more generally. In some cases, the lack of elements or conditions which people strongly and directly associate with person-centred support emerge as key barriers in the way of taking it forward.

People think they know what you want

Service users particularly, highlighted barriers which they felt were caused by the assumptions of face-to-face workers and family carers that they knew what was right for service users – 'what you can and cannot do'. Such assumptions pre-empted the possibility of hearing and including what service users had to say.

> They believe they know what we need and they don't accept it when we say they are wrong or tell them what we really need.

> People think they know what you want.

These assumptions, they said, were frequently not accurate. They could make it difficult for service users to make their voices heard. Attitudes based on assumptions of 'knowing best' could be a significant barrier to person-centred support on an individual basis and fitted poorly with a person-centred approach to practice and support.

One participant said that some staff

> Lack the right values i.e. [that] every person can contribute, has gifts and is valuable.

Inflexibility

One person commented:

> [Services] saying 'we've always done it this way' is a barrier.

Such a backward-looking approach, which is not open to new ideas or individual preferences, is at odds with person-centred support. Many service users referred to services being inflexible and either unwilling or unable to respond to individual needs. Several service users spoke particularly about the inflexibility of social services 'home-care' services.

> I was told 'we've only got a 'slot' at such and such a time'.

> If you want home care you are told when you can have it basically.

> I was working full time and I was told the only slot they could fit me into in the morning was 10.30, and I have been getting to work at 7.30 in the morning, but I just couldn't cope on my own any more. And they said 'Oh well we can slot you in at 10.30 there is no other time available'.

Lack of information

Some service users made it clear that they did not even have basic information about some key issues. For example:

> I do use these groups well, and I didn't even know what a bloody advocate was. Nobody had told us about that … I was a bit annoyed when they didn't explain about an advocate, I have been in the hospital for about 3 years and nobody told me nothing.

There was strong agreement that a lack of information about who qualifies for a service and how to make changes to a service were major barriers to person-centred support. The effect of such a lack of information was to disempower people, as they could not know what their options were and therefore were unable to make informed decisions. As one service user put it:

> It's hard to make choices if you don't know what the options are.

Lack of adequate information could be both a cause and effect of a lack or loss of confidence. Several people felt it had a particularly detrimental effect on people who had recently become disabled following accident or onset of illness. They did not have the time to develop an awareness of service options and often lacked supportive relationships with other service users.

> It is a very bewildering world, there is so much information out there that we trip over all the time but don't actually realise exists and it is about gathering that information. A lot of people don't actually know what is going on round the corner from where they live.

> This lack of information can lead to a lack of confidence.

> People don't have the confidence to speak out and say 'this is what I want'.

Lack of information also emerged as a barrier to face-to-face workers, who often did not have the tools to direct service users to relevant services or support options.

An exchange between three service users in one group discussion about this topic highlighted the complex difficulties inadequate information posed.

> I do think we should get much more support in what we do because we don't know really what support we can ask for and nobody is there to tell us.

> There is always an assumption that you already know, and when people find out you don't know something they are so surprised, yet it has never struck them to actually tell you.

> I think people will come and ask you what you want but you don't necessarily always know what is available to ask for what you want, if you understand what I mean. So there will always be somebody who will ask but you won't necessarily know what there is to ask for.

One face-to-face worker spoke about how difficult it must be for people who do not speak English as a first language to access information about services.

> It must be absolutely a nightmare just to even begin to understand the meaning of some of the language, it must be a nightmare, I don't understand some of it and I work in it. It is just appalling.

A service user said:

> Statutory agencies have got to be far more attuned to different people's needs and how they want information and how they can take it in to make decisions. So it is informed choice, informed decisions.

Money and resources

Many people identified lack of money and/or resources as a barrier to person-centred support. This emerged as a major issue, but also a complex one. While adequate funding was identified as a key requirement for person-centred support, it was not seen as necessarily sufficient on its own. Participants thought that decisions about the provision of services were made primarily on a financial basis.

> Money is a barrier – it's a lot to do with money. (Face-to-face practitioner)

> It all seems to boil down to funding. There is only so much money available to each council and this has to be allocated to each group. Many groups seem to be at the bottom of the list. (Service user)

> We have been hit by a lot of Local Authority service cuts which has had a big impact, sometimes the talk doesn't match the outcome. (Manager)

The words 'money' and 'resources' were used almost interchangeably, particularly by managers and face-to-face workers. 'Resources' can mean much more than money, but frequently the word 'resources' was used when 'money' would have been more accurate.

While many people felt that lack of money was a major barrier to person-centred support, others thought that money was also often wasted. Others suggested that lack of money was used as an excuse by managers who were not person-centred in their approach. Thus one service user said that services are:

> Too quick to blame money as a reason not to do things.

Service users suggested that, in some cases, the real barrier might be the approach of those commissioning or providing services rather than a lack of money.

> Done as it should be, it should cost less time and resources in the long run, many people don't see it can save time and money. Attitudes!

> Funding is a big issue. Also very often I find people have decided in advance what the money is going to be spent on. So you can ask until you are blue in the face but if it doesn't fit with what they have planned you are not going to get it.

One manager who has been involved in raising money for a service user group was optimistic and said:

> There is a huge amount of money out there, you just have to have the skills, or you have to know people who do have the skills, to put the funding application together.

Some people, however, expressed frustration about existing patterns and priorities of funding. While there might be money for initiatives or start-ups, for example in the

voluntary sector, ongoing funding for existing mainstream services, was much more difficult to get hold of, and this created big problems for person-centred support.

> Funding is fine in the short term, but long term stuff, most trusts and funds don't want to support your on-going staffing costs.

As one manager said about funding problems:

> All I can say is I have been in the job 30 years and I have heard the same story for 30 years.

Local authority charging policies

Several participants, most of whom were service users, raised the issue of local authority charging policies for social care services. Such policies mean that many social care service users have to pay for the care services they receive, effectively being penalised for having an impairment. These charges were viewed as inequitable and as a disincentive for people to use services. The cost could either deter people from requesting a service in the first place or cause them to limit what they received on the basis of how much they felt they could afford to contribute. Such charging policies have the effect of encouraging things to get worse, rather than preventing problems deteriorating. Service users do not even always know whether they will be required to pay towards their care or how much. One service user said:

> All [service users] are thinking is maybe they will be charged or something, they don't know if there is free help for them.

Staff time and approach

Some participants identified both the amount of time that workers had available to support service users and the quality of the support they offered as barriers. A picture emerged of 'quality time' often not being available.

Managers and face-to-face workers emphasised that their services cannot afford to dedicate as much time to supporting service users one-to-one as they would like.

> There is a need for more support in person-centred planning: for example, more staff.

> It is actually if you don't get the chance to have that relationship with someone, to build up knowledge and a relationship, that is where the first barrier is I think.

> For us, basically being residential we can have 14 people living in one house with three members of staff. So there becomes a limit to how much you can actually work with people in a person-centred way. It is very difficult to do a lot of one-to-one work.

> It is not about having a blanket approach. It is about an approach for each individual, it is very time consuming. We just don't seem to have that time.

This lack of practitioner time can be expected to become a barrier in the way of forming relationships with service users, keeping in contact and holding regular meetings with them, as well as in the way of supporting the implementation of a service user's plan. For example it is likely to create difficulties in the way of supporting someone one-to-one to pursue a hobby or pastime. One service user said that person-centred support in his area was breaking down owing to a lack of available staff time.

Many service users told of negative experiences due to the attitudes or approach of staff they have had working with them. Others thought that staff had received insufficient training or were put under too much time pressure to work effectively. Some felt that some staff were not suitable to work with service users. They said, for example:

> There's a lack of knowledge and experience.

> Even when she does come round she is limited to what she can do.

> It seems, just from looking at our staff, and also looking at what they say, that sometimes it very much comes down to the individual who you are working with.

Risk and regulations

There were frequent references in discussions to the impact of issues and notions of risk and to the various rules and regulations under which services operate in relation to risk. Risk is now a matter that is raised at all levels of social care, from insurance, legal responsibilities and 'health and safety' to individual occupational practice. Managers and face-to-face workers said that their perceived responsibility to 'keep people safe' (both service users and staff) could be at odds with a person-centred approach.

> I think that often the restraints are about covering our backs, it feels like, so therefore it stops us sometimes delivering or enabling us to be very person-centred.

Participants felt that the need to conduct risk assessments about activities involving service users could become a 'barrier to trying new things'. The point was, for example, raised by a worker from a residential home. She said this rose from services being accountable and responsible for the health and safety of those using their services. This could have an adverse impact on the range of activities individual service users were encouraged to undertake. Top-down pressures holding them formally accountable for the health and safety of service users was a concern among both face-to-face practitioners and managers.

However, there was concern among service users that health and safety was used as an excuse by services for not providing person-centred support.

These barriers were particularly evident among those working in mental health services. The impact of certain legal sections of the (1983) Mental Health Act were highlighted.

Ideally personal services would allow people to choose what they do on a daily basis but with the Mental Health Act it's not possible … We have some statutory obligations that we must do and how do you empower choice amongst that?

Some of my patients could be on a section which means they couldn't go into the community, they couldn't access community services if they wanted to, they certainly couldn't live in the community. Although ideally we would like it to be the person, the service user's, choice what they do on a daily basis, sometimes we can't help them.

One service user living under a court order said:

I live in a hospital, and do what others tell me to do. What I really want is to be out in the community and have trust. I think one day it will happen.

One manager said:

Working in a person-centred way with homeless people might mean accepting and supporting their choice to continue on the streets or taking drugs, which services find difficult to accept.

Face-to-face workers talked about the possible risks they took trying to work in a person-centred way:

But it is knowing when to take that step back and being confident they are making the right decision because some of the decisions will be the risk stuff and that is when it gets hairy for a worker. Because you don't want to end up splashed across the newspapers, this social worker neglected this older person and they have been dead on the floor for a week. You have got that at the back of your mind when you go in.

This was an issue which service users were sometimes aware of:

So there are restrictions on the workers in a way in what they can do and what they can't do.

Communication

Communication between statutory services and those from other sectors was highlighted as a barrier by one face-to-face worker who said:

> There is a need for more communication between different groups. Poor communication causes a lack of co-ordination.

These problems seem to relate closely to the provision of information. Problems of communication were identified both between different sectors (private, state and voluntary) and different policy and service areas. Participants explained that one service may be unaware of another's existence and is unlikely to have any printed information about it.

> They don't communicate with each other, all the various groups I use. There is no co-ordination. (Service user)

Some practitioners felt that they should have a greater role in improving communication because of their crucial role working directly with service users – if person-centred support was to be made more of a reality.

> I think we should take responsibility for the chain of communication. We are working directly with people who are using the service, who know what they want and what they are telling us. And it is up to us to take responsibility in the chain to pass that information to other services that person is using in order to tailor it to be person-centred. (Face-to-face worker)

Culture and language

Particular barriers were identified for some service users from black and minority ethnic groups. For people for whom English is not their first language, without suitably skilled workers or reliable and accessible interpreting services, communication barriers arise. Members of such communities may not know what services are available or be reluctant to use them after negative experiences arising because of services' lack of cultural awareness or sensitivity. The example was given of day services that did not offer Halal meals for Muslim service users. This example relates to a basic need and as such is the tip of an iceberg of much more complex cultural needs. If this basic need is not met what are the chances of these other complex needs being met?

Tensions were also identified relating to government and broader social attitudes expressed in current debate about multiculturalism and integration. Some participants thought that in the current climate, where the assimilation of minority ethnic groups is emphasised, services set up to meet the particular needs of service users from, for example, British Asian communities could come under threat. This was despite the positive impact that some such services have had in offering person-centred support.

> There is a lot of talk in government about multi-racialism versus multi-culturalism. Now the groups of people I have worked with, a lot of them haven't received the services and we have set up a self-advocacy group and support group, largely of people who are Muslim men, and a few women, and a few other people from other communities. Now that is good for that group of people because they have got people from their own culture, they have can have shared language and understanding. But that is not the way the government wants [such] things and I have to work to the bigger government agenda. So there is tension between what the government wants and what some of these individuals will benefit from and what they want to start off with. (Face-to-face practitioner)

Institutionalisation

There was a feeling among face-to-face workers that 'institutionalised thinking' among service users was a barrier to person-centred support. This was not said as a negative criticism of service users. Instead, what they meant was that many people with a long history of using traditional services to which they are expected

to adapt have become institutionalised and have not had the opportunity to develop independent living and decision-making skills. Such institutionalised living can develop in all services, including domiciliary services and not only the residential provision traditionally associated with it.

> I work in a service where we have people who have been there for a long, long time, some have been there for 30 years, 20 years. It is very common for a lot of our service users to have been at the service for that length of time and for them to change from being in a position where they were told what their care would be and what would happen, to then having more involvement in it must be quite difficult for them. We are still in the process of trying to overcome those barriers. (Face-to-face worker)

Service users, however, expressed similar concerns:

> I think it is quite frightening for me to leave the hospital because I have been there a long time but the powers that be want me out and I am going to be out. It is all to do with money.

> People lose identities within institutions and I think unless you have a clear idea of your own identity and who you are as a person, that (setting goals) is very difficult.

Service users may be scared to break habits and move on. This creates a real need for support prior to discussions about what choices people want to make. This support may be providing by offering information, advice or training. Workers and managers said:

> I also think that if someone has experienced a culture of not feeling empowered it is actually quite a shift. And working in a very person-centred way also means people taking responsibility and I don't think one can come without the other, freedom and responsibility have to go hand in hand, so there's a price to pay for choice. And I think that needs to be made quite clear and I think having choice can be quite a daunting prospect. Decision making generally is quite a daunting prospect for all of us, making decisions every day and if its something we are not very skilled in it can be quite challenging.

> [It requires] actually knowing who they are and being comfortable within their own skin before they can even make choices.

The fundamental implications inherent in making the shift to person-centred support were highlighted by this exchange. It will not necessarily be just how services operate that will need to change, but the very nature of services and support. This is a key point which needs to be emphasised.

> One main barrier is the idea that its the documentation and the thing itself belong to the staff not to the service users. It's hard for us to get our service users, some who have been with us for 30 years to accept that it is their document and plan and that they can take ownership of it. (Manager)

> [Is that a generational thing?)] I think it is an institutional problem. Maple View (anonymised name of home) has been there for 40 years and was run along very old fashioned lines until about 3 years ago, so there are a lot of things that need to change, to empower the service users to take part in the running of the service, to realise that they can complain and also tell us how good the service is – mainly that it is their service and they can take part in the running of it. (Manager)

> But older people don't grow up in a home in a street with just other older people on it do they?

> No.

> So why segregate them away?

Negative experiences of user involvement

A barrier to person-centred support mainly identified by service users was the failure to employ effective and meaningful service user involvement and consultation in the design and improvement of services. Service users reported negative experiences of user involvement. Considerable frustration was expressed by people who had contributed their time and effort in the hope of improvements being made to services, with no tangible result. This reflects much broader findings in the fields of social care and health. Participants reported three key failings. These were:

- a lack of support;

- a lack of feedback;

- a perception that involvement had not resulted in improvements being made.

Service users said:

> We also go to a lot of meetings and you are discussing things and you never hear anything about it afterwards. You never know where that discussion went or what did head office think to it, what they had to say about it, what is going to be done about it. So very often you feel I have just wasted my time going to it.

> I'm angry with people asking about what you want and then not following it through.

> You report things and they give you a date but nothing is ever done right … I'm actually on a residents' action committee for [name of housing association], I take the complaints. It goes up to another level. It goes from there, (pause) it's like going round in a circle.

> A lot of people don't exactly understand what this supporting people consists of. I mean when they first came round they asked us what we needed. We said we needed dropped kerbs for the wheelchairs. Instead of giving us dropped kerbs we got handrails put outside the house. So what we needed we did not get, and we feel we should be told why and what we are entitled to.

Workers reported frustration from their experience of user involvement:

> Because they (service users) weren't supported effectively, they weren't really given guidance on what their responsibilities were and what they could and couldn't do, that was very difficult.

A manager said

> There has been an awful lot of: 'we know it [user involvement] is a good idea so let's do it', but we don't know how to do it well, which is what we are trying to do.

One service user spoke about the lack of feedback received following a process of user involvement and what seemed to be the assumption that it was for service users to find out.

> We could contact them but why should we have to go on the phone? Why should we have to go round to their buildings? We have got our own life of where we are and the best we can make of it and we haven't really got time to go to an office to say 'give us the feedback', they should be sending it to us.

Several people spoke of service providers not providing feedback following meetings. One person spoke of their frustration with the organisation and administration of involvement, which raised questions about how seriously it was being taken.

> User-involvement hasn't worked in my area. It takes a long time to pay you £20 to attend. It takes months and months and is poorly organised. Organisations still only invite one user, papers come late, and notification comes the day before. This all shows that they are not listening or not acting on what's said.

There was little sign that issues of access were routinely being seriously addressed to ensure that a wide range of service users could be involved on equal terms. Lack of time given for preparation can for example have a disproportionate impact on service users who have learning difficulties or visual impairments. Lack of notice may make it especially difficult for service users who require support with mobility to participate because of their need to arrange transport, parking or personal assistance. These then become barriers to participation and to service users having a say about their services.

Such negative experiences may explain the frequently negative attitudes expressed about the approach of services towards user involvement. Service users said:

I think there is a deliberate effort on behalf of organisational structures to block people's understanding of what is needed to change things.

The organisation or council holds all the cards.

They're looking for the views they're looking for.

Unfortunately, these negative experiences are also closely reflected in the findings of other research on user involvement (Branfield and Beresford, 2006)

Outcome measurement

There was a widespread concern among managers of services about needing to demonstrate the effectiveness of person-centred support. Managers were acutely aware of the importance of being able to measure outcomes in order to satisfy their funders and to meet 'performance indicators' required by government. Many thought that the outcomes of person-centred services were difficult to measure, as they were 'soft' rather than 'hard' targets. Some services, it appears, find it difficult to measure the added value associated with person-centred services through progress made by individual service users, for example in gaining independence and in learning new skills.

This was seen as a barrier to person-centred support because of the pressure on services to demonstrate the validity of their approach towards service delivery to funders. There was concern that services which were not able to show accurate measurements for outcomes achieved could be vulnerable. Workers and managers from outreach services and services that saw prevention as part of their role indicated a particular concern in justifying their outcomes when being judged against local authority matrices of need. One local authority service was concerned that their service, which was valued by service users, could be regarded as non-essential (under tightening eligibility criteria) and therefore be at risk of cut-backs.

One manager said that pressure on services to meet indicators could result in a switch away from a focus on the individual service user. This suggests a danger of services being shaped and organised to satisfy monitoring requirements, rather than necessarily being truly person-centred.

Yet, it was only necessary to listen to service users to hear how person-centred support worked to support independence and independent living. For example:

> Yes, it has made me a lot stronger person. I can see myself moving out, getting my own flat and getting a job in the future, doing all the normal stuff that a teenager would do. (Service user)

It is clearly very important that the views, experience and experiential knowledge of service users are taken into account when assessing person-centred support. Such approaches to support are also natural candidates for moving beyond traditional professional and managerialist outcome measures to more user-defined ones.

Eligibility for support

Many managers and front-line workers referred to local authority 'eligibility criteria' as being a significant barrier to person-centred support. These are the critieria which are used to determine whether or not service users qualify to receive support. They vary from authority to authority and are not based on agreed understandings of rights or need, or an independent living approach to support. Four official levels of need are currently identified – critical, substantial, moderate and low – and local authorities are increasingly restricting their support to people they include in the fourth category as being in 'critical' need. This works against a preventative approach to the provision of support and means that service users must show how little they can do in order to receive support, rather than what will help them live their lives as fully as possible.

Participants pointed out that such criteria work in the opposite way to the positive approach discussed in the second chapter of this report. They focus on negatives: on what a person can't cannot do, not what a person can do. A local authority worker said:

> And because the bar for people to be eligible for our service is so high, it makes it virtually impossible to do the person-centred approach because what they want does not fall within the eligibility criteria of our service.

> To be eligible for our services is constantly being put higher and higher ….so your needs have got to be critical before you become eligible for our services, which makes it impossible … for us to actually access services.

Another face-to-face worker highlighted the failings of this narrow accountancy-based approach to funding support:

> We are having to cut away services that have been funded to the low dependency. But that's short-sighted. If you cut out low dependency and moderate dependency services and only offer financial help for the critical then they are all going to be critical very, very shortly and you are going to have less money to go around, and I don't understand why they don't see that.

One service user who has recently moved to live independently in her own flat said that she was worried because she does not receive enough support. She said she would like more initial support to help with learning new skills such as cooking, but was told that she was not eligible.

Others said:

> The problem with the assessment process is that often the guys at the top with the money say to the people who are doing the assessment, we have only got this amount of money, and they adjust the assessment according to that knowledge.

> That is right. That is what has happened. It seems to be only the people that are almost on their death beds, that hit the top criteria, get what they want.

A manager highlighted the way in which government policy had worked against person-centred support, making clear that barriers may go as far as government level:

But there are classic cases of where social services, on instructions from the government, have said you are to decide at what level you will deliver care. A lot of the preventative work went out of the window, the shopping, the cleaning, the ironing, and so on. But the rules said, no social services provides personal care, social care not person-centred care, and we don't do washing, cleaning and ironing. So it is the opposite of that is what we want.

Family carers

Some people who had been involved with person-centred support (often through person-centred planning meetings) talked about the barriers they had encountered from family members speaking on service users' behalf. The problem of family 'carers' speaking and acting on behalf of service users is one that service users and user organisations have frequently highlighted in relation to traditional services and service relationships. Their views about what the service user wants or needs become the accepted ones, rather than the service user's own views. Practitioners commented:

Quite often families will intervene on behalf of a person and say 'what they really want is …', and be quite prescriptive in what they really want and it is about, I guess giving people the courage really to just, you know, to have a bit of space and think about what they would really like for themselves and to have people to actually just voice that and them being able to advocate.

So we will work one-to-one with a person and quite often you will have social workers or parents or carers saying, 'No this is what we want for that person', and then that person saying, 'well I know that but really I don't want to do that'. So what we try and do is give them the space to explore what they want to do. So we will try and make it as easy for them as possible so they can get the opportunity and experience.

As these examples indicate, offering support to the individual service user to support their decision-making becomes part of the process of person-centred support, along with an element of advocacy in working with family and friends. This role is perhaps best described as facilitating the process of person-centred planning and removing the potential barrier that fears about risk and lower expectations on the part of service users' loved ones can sometimes create.

Geographic inequality

There is a lack of equity in access to support services not only because of what has come to be called the 'post code lottery'. Some areas just do not have the services that some service users need. People commented on the unequal opportunities available for support in different areas of Britain. This happened at least in part because people at the Get Together event found out about the services provided and received by others in the different sites and localities included in the project. This led some people to comment that they had 'nothing like that' in their own area. Such barriers arose because of both the geographical nature of specific areas and local traditions of service provision.

It's a constant struggle because of the environment and the geographical area we live in. We have problems reaching the isolated people. (Manager)

Everything has changed and there is nothing in [place name] where they live that can provide them with the service that he needs. Nothing that stimulates his memory, there is nothing. So you can sit and talk person centred all you like, the services are not there. (Face-to-face worker)

Transport

Some people identified transport or the inadequacy and inaccessibility of transport, as a key barrier. Problems with transport were said to be a barrier to accessing services and more generally to accessing community resources. This barrier is particularly acute for people who live in rural areas where services and community resources may be a considerable distance away and where accessible transport may be very limited. The cost of getting accessible transport was also highlighted as a barrier. As service users said:

> If you have the money then fair enough, it's just if you want to get out to the next town you have to go in a vehicle and if you ain't got a driver or a vehicle, which they [services] don't always have, you can't do that.

> I personally can't go out on my own at home on public transport simply because 99% of the time the ramps don't work or the drivers won't get out and lift the ramps because it is a safety risk. A lot of buses [where I live] have got them, but they are either not working or there is something wrong with them. I don't feel confident if I went out on my own that I would be able to get from A to B and back again without difficulty.

Individualism

Person-centred support highlights the value and importance of matching support to individuals as a way of their achieving their full potential. One person spoke of a less helpful aspect of individualism. They drew a distinction between independence and individualism. They felt that society was increasingly organised around the individual and that such individualism might not be what service users want. For example, the idea of getting their own flat can be a disincentive to moving towards independent living for someone who fears becoming isolated. Therefore they felt it was important that person-centred support offered service users a range of options to choose from and the support to make changes over time.

Ageism

Some participants who were older people or who worked in older people's services, thought that age discrimination continued to be a major barrier to person-centred support.

> Older people tend to get overlooked, and it seems that they are treated in a discriminatory way.

They felt that other groups of service users either received more support or a more person-centred service than older people.

> I think there's more flexibility for people with learning support needs, and disabilities than there is for older people. It's age discrimination.

One person commented that it was harder to qualify for a service as an older person, suggesting that assessors had a lower expectation of what older people can expect to achieve.

Differences in perspective

The three constituencies, service users, face-to-face practitioners and managers, generally identified similar barriers in the way of person-centred support. Sometimes it was the emphasis that was different. For example, many people viewed inadequate funding as a barrier. However, it was service users who said they sometimes thought funding issues were used as an excuse by services not to do things.

All three groups of stakeholders identified the following barriers:

• information;

• money;

• communication;

• institutionalisation;

• culture and language;

• eligibility for services;

• geography;

• transport.

Service users also identified 'people thinking they know what you want', inflexibility, local authority charging policies and negative experiences of involvement, as barriers. Face-to-face practitioners in addition highlighted a lack of staff time and families speaking for service users as barriers. Managers also identified a lack of staff time and the difficulty of measuring outcomes.

4 How can we overcome the barriers?

The third question we wanted to consider was: How could the barriers identified as blocking person-centred support be overcome? While participants had much to say about these barriers, they also had many ideas and suggestions about how to deal with them. This was true of all three groups of stakeholders: service users, face-to-face practitioners and managers.

Participants were clear that changes were needed in the way in which services and support were provided. They expressed great frustration at the impact that the barriers which we reported in the last chapter were having on the lives of individual service users. From discussions at the Get Together event, it became apparent that there were many different opinions about how to overcome barriers. Some people spoke about changes that had improved their own services. Others referred to changes they would like to see in the future.

In this chapter, we have again tried, wherever possible, to group together people's thoughts and ideas according to the themes that emerged from them. Underpinning people's thoughts about person-centred support and ways of taking it forward was a clear belief that it represented a principled and value-based approach to support, rather than a set of mechanistic tools or techniques. There often seems to be a tendency for developments in personal social services/social care to be reduced to simplistic and standardised ways of working and doing things. Participants in the Get Together event offered a clear warning that such an approach would be no more helpful in taking forward new ways of working than in reforming old systems of support.

Participation

Service users made it clear that, for them, the most important way of overcoming the barriers to person-centred support was through increased user involvement or participation. They talked about both individual involvement and collective involvement through working in service user groups and organisations.

The provision of accessible information was seen as a necessary precondition for effective participation. Service users thought it was important, however, that information should not be seen as an alternative to involvement or taken to mean involvement on its own, saying 'Involve, not just inform'.

They argued that information should be circulated both by service users and groups and organisations of service users themselves. One way of doing this that was seen as particularly valuable was through groups of service users coming together and sharing/circulating their accumulated knowledge. Given access to this information, some people suggested that service users should be involved in finding their own solutions (at an individual level) or in finding solutions to barriers faced by groups of service users in general.

Participants described a range of ways in which user involvement was currently taking place or being developed in project partner services. Below are some of the examples they gave, including service users involved as volunteers, as representatives on formal bodies and consulting with other service users.

> One of the things that we are looking to get going is a representative model so that people who use our services have representation at the different meetings and groups that already exist where plans are being made about how we provide our services, or decisions are being made about the future services that we provide. So we are just looking to get that going. (Face-to-face worker)

> We have always involved members of the activity centre as volunteers as well and we have various steering groups. (Face-to-face worker)

> Before they brought this rule out [about involving service users], I was doing it you see and I got some older people to go and interview the permanent residents and interview the temporary people. (Face-to-face worker)

> And the fact that we have got service users on our partnership board, that in itself has influenced the whole way in which the partnership board works in terms of we present things in a much more straightforward way. Which I think cuts to the issues much more than if it is professionals just talking jargon. (Manager)

It was clear, however, that many participants felt the process should go much further. The wanted to see user involvement extended to the management and running of services and support. As one person put it:

> Service users need to be involved in the decision-making process.

There was also widespread support for the idea that service users could and should, be involved in offering 'peer support', 'helping other service users' in a variety of ways, including as trainers, facilitators, advocates and workers.

> Service users also come along. They have formed their own links so that other service users can see them about, you know, if they need needles [for injecting], or if they are having problems, [drug] withdrawal problems or other symptoms, external problems with families etc. So there are lots of different places. Either they go to the staff or they can go to service users themselves. (Manager)

> Front-line workers can support users to be empowered and not be afraid of the empowered user. (Service user)

Some people echoed the slogan of the disabled people's movement, 'Nothing about us, without us' by saying that the principle underpinning user involvement should be 'By the people, for the people'.

Many people thought that there should be increased service user involvement in services' management committees and meetings. One manager talked of a related development:

What we are trying to do, we always have residents meetings so anyone who wants to come and sit there and talk to management about issues that they have, but we are going beyond that now. We do have those but we are also having with clients … their own separate meetings where there are no staff there at all. In order to facilitate that we have got clients that have actually been trained in how to take the meetings and how to turn up, at as many of the kind of induction courses that are done for staff – training sessions done for staff.

At least one service was said to be working towards service user control by 'Giving service users the final say'.

This organisation already had a number of service users on their management committee. This, they said, ensured that service users were not just informed about developments, but actively contributed to them. One person from the service said that, if an idea was not approved by service users, it did not go ahead. Others talked about different ways in which service users were involved in their organisations.

Certainly at the centre I work at we have a management committee of representatives of service users who make decisions about anything to do with the centre and any changes, financial, money, funding that we have, how we are going to spend it. So being involved in the decision making process. (Face-to-face worker)

Like I have meetings with service users and we talk about what we are going to do with some money we have been given and what to buy with it. Also, if any of the service users wanted to go on training for recruitment and selection, or for chairing meetings, or for becoming more involved in the national service user groups, that is available as well. (Manager)

[Name of Hospital magazine] – I love doing it, it is a thing I am developing, and it is something that everyone likes reading. (Service user)

We set up a group with service users to encourage them to take control more of the services and activities they do in-house. […] So rather than providing and meeting and delivering it ourselves as staff members it is allowing them to take charge for themselves. (Face-to-face worker)

Involve, involve, involve, don't just ask them once, involve, feedback, keep them interested. (Manager)

> And I think there is the element of challenge. How do people with a [an impairment] or old age make a complaint or bring about change. What is available to help people bring about change other than making a formal complaint (Face-to-face worker)

People reported and suggested a wide range of possible approaches to and roles for service user participation. These included:

- consultations;

- focus groups;

- service user committees;

- input to service/management meetings;

- involvement in interviewing staff;

- supporting other service users;

- monitoring and evaluating services;

- training face-to-face workers;

- finding solutions;

- decision-making;

- being part of delivering services;

- having the final say.

One group of managers said it was important to recognise the progress made so far in making services more person-centred. They thought that services were listening to service users more now than ever before. In addition, many managers and face-to-face workers thought that health services were significantly behind social care services or the voluntary sector in the development of person-centred support.

Improving consultation and involvement

Participants, as we have seen, also identified shortcomings in existing user involvement in their services. Thus they were also keen to improve arrangements for involvement and saw this as important in overcoming obstacles in the way of person-centred support. There was universal support for the principle of service user involvement despite service users' sometimes negative individual experiences of it. Consultation is generally seen as a low level of service user involvement, but participants nonetheless felt that often it could be done much better. A key way in which user involvement and consultations could be improved, it was felt (and this takes us back to one of the barriers identified earlier), was by ensuring that participants received proper *feedback*. One service user said:

> Keep service users informed and involved. If there is a meeting behind closed doors, either service users should be able to get involved or they should get information about what was said.

Lack of feedback led to frustration among service users, who might then think twice about getting involved in future consultation meetings. Service users felt that it should be made clear to participants from the outset what the likely impact of their views could be when they become involved in a consultation exercise. Many felt frustrated at the lack of noticeable improvements to services following consultation. This led them to question whether their involvement was valued or meaningful.

The comments of service users point to a series of guiding principles for improving practice in user involvement. They said that it was important to:

- give advance notice of meetings;

- ensure that agendas and supporting paperwork are circulated well in advance;

- ensure that agendas and supporting paperwork are made available in accessible formats;

- select venues that are fully accessible;

- take into consideration the support needs of service users during meetings;

- ensure that more than one service user is invited (on to any representative committee or forum);

- facilitate the involvement of people facing multiple barriers, for example disabled people from black and minority ethnic groups.

Trust

One service user said: 'Believe in people, it works!'

Many face-to-face workers and managers spoke about the importance of showing trust and confidence in service users. They reported that this positive approach supported people to gain confidence, which they saw as a valuable component of person-centred support: 'Give individuals the confidence to get involved.'

Some comments followed on from the views reported in Chapter 2 about the importance of relationships to person-centred support:

> [Person-centred support] is based on trust and honesty, the relationship that we have. (Service user)

> Actually that building a relationship where people feel as though their self-esteem and their self-awareness [are] raised to actually think about what they want, because maybe that is something that they have never really been asked. (Face-to-face worker)

Ways of encouraging the development and maintenance of the relationship between practitioners and service users emerged as important in reducing barriers to person-centred practice.

The issue of risk and supporting positive risk taking again emerged in this context. Participants were concerned that it was difficult for service users to develop independent living skills without having opportunities to learn by experience – which necessarily could include making some mistakes and taking some risks. Insulating people from perceived hazards could prevent them from learning to make choices. Clearly, there is a difficult balance to be found between trust and risk aversion, but being overprotective, which can be tempting for both practitioners and family members, is ultimately unlikely to be helpful if people are to take more control of their lives. As one practitioner said:

> I think you have to be able to take down the protection and allow people to make mistakes … I am one of those people that have to put their finger

in the fire to know that it is hot. I think going through the experiences … is where real learning takes place and it is painful to watch. I think anybody who cares for anybody, it is actually a painful process to watch and trying to be quiet and just be there maybe to pick up the pieces sometimes is maybe what we have to do.

Several workers reported the frustration they felt at working in systems that imposed restrictions on opportunities for service users because of the possibility of risk.

A positive approach

As we reported in Chapter 2, many people emphasised the importance of focusing on the positive qualities that individuals have, rather than the negatives to make person-centred support more of a reality. Key methods for doing this include promoting active involvement and emphasising individual contributions towards achievements and goals. One person spoke of the benefits of co-production which has a focus on community involvement and the participation of people who are marginalised and excluded.

Someone else explained how this approach has led to service users offering support to other service users. It could lead to the empowerment of service users through active participation rather than through their passive receipt of services.

One worker said:

> As a society what we tend to do is focus in on people's [impairments] and inability in doing certain things. And what we actually should be doing is focusing on their active contribution and their active participation and the positive things they have to bring. What *we* are actually saying to people is 'you are not just coming here to use the services you are coming here to contribute to a community'.

A service user commented:

> That is no way for us to go on as a community. We have got to change that negative attitude which is outside …. When you are on that receiving end you suddenly take on a negative frame of mind when it is yourself or your family, but you can easily become very negative. That is a change that has got to happen, that barrier of negativity has to be addressed.

Examples were given from people's experience of setting up groups in their locality. Groups had been set up that responded to the interests of local people and attracted membership. These groups strengthened networks, as well as offering leisure opportunities. They also encouraged active participation among service users and their integration in the local community. One manager said:

> [What] we found to be most effective is finding out what people's interests are and getting them involved in planning their own – kind of, 'What do you want to do? What do you want to get out of it?'

Another example was given of a service that supported a group of people whose day service was under threat of closure. The worker supported the group of stakeholders to come together, form a committee and raise funds to safeguard the future of the service. The group was able to become independent and take control of the day service.

Advancing and promoting good practice

There is currently a lack of clarity and wider awareness as to what constitutes good practice in taking forward person-centred support. Indeed, one of the aims of this report, and the project it is part of is to develop understanding in this area. While specific approaches such as person-centred planning have developed detailed guidance for good practice, this is not true for the philosophy of person-centred support more generally.

Many participants saw a strong need to share and circulate good practice in person-centred support. Many thought that the promotion of good practice could contribute towards the overall quality of services. Some people said that it would be useful to have workshops or practice forums where people could 'Exchange ideas and share what is working well'.

Participants supported the idea of a network to do this. Some people suggested that case studies or 'success stories' would help. There was a sense that making changes towards more person-centred services can be difficult and that some managers and workers feel isolated. There were several references to 'not re-inventing the wheel' as well as the importance of the mutual support that can arise from discussing practice with people who are in similar situations and having similar experiences.

One discussion group raised the idea of having 'champions' for person-centred support within each service. This role would include advocating person-centred approaches and answering colleagues' queries. It would help to keep person-centred support on the agenda and assist individual workers to adopt it and take it forward.

Many people thought that more work needed to be done to raise awareness of the advantages of person-centred support. They thought it was time to promote it more systematically, developing a more strategic approach to advancing it. One service user said this should be targeted at 'Councils, service providers, families and those who can benefit'.

People coming from services who thought they were person-centred felt that they faced a lack of awareness and understanding from these groups when they tried to spread or market their services. They said:

> Let's work together to show what person-centred work has done for us, and can do for others.

> We don't get out there and shout enough about it.

One manager commented:

> We made a DVD of clients talking about person-centred planning and showed the tools being used, and it is about how it made them feel and we use that in some of the seminars around the country. So other providers can see the sort of stuff we are doing so that they might feel inspired to do some of it themselves.

Several people suggested using the media to raise public awareness of person-centred services. A service user said that it was important for people to 'Shout out "I am me and I have achieved this!"'

Information

The issue of information cropped up in every aspect of discussion about person-centred support. A key message from participants was that the provision of high-quality, up-to-date and accessible information was an essential element of person-centred services and support. This included information that is in a range of accessible formats for disabled people and that is made available in community languages. Many people said that, without information, people could not make (informed) choices. The importance of information was emphasised by both service users and face-to-face practitioners working with them. Workers said it was essential for them to have good-quality information if they were to be able to assist service users effectively in making decisions. They said 'If you don't know what is available, how can you make a decision?'

Some people said it would be valuable to have moving-on events for service users. These events could provide information for workers and family carers, as well as service users themselves. They would enable these three different constituencies

to talk about the different options available and to get more realistic and shared understanding of what might be possible for individual service users.

> One of the things that we organise in our area are what we call moving on events and that is 3-monthly events where service providers, commissioners of service, service users, family carers, all come together and the reason that they are called moving on workshops is it is about how do we support people in a more person-centred way to move on in anything that they want to do. They are really enjoyable get togethers and I think pretty useful as well because people usually say how much they have enjoyed it and how useful they found it. (Manager)

> One of the things that people find really useful at those events is that commissioners of services can give feedback as to this is what we are doing in the area, and service providers can give feedback as well and then hear from people about is that making a difference or not. So I think that is really useful. (Manager)

One service user said:

> I think it should be one big book that has got everything in it that you could need.

Others reiterated the general point about the importance of information for making person-centred support real.

> I think they should have more literature about it, more meetings with people to tell us and explain things to us. (Service user)

> We would like more information about the help that we can get. (Service user)

It was also suggested that to help them navigate services, some service users might need more assistance.

> Finding your way through the system is difficult, particularly for older people. There is a need for mentoring to help them through the system. It's a maze. (Service user)

> That is about being given that information and that is very helpful because I can't do it all myself and I can't access all the things and I don't have the skills to deal with all of that. (Service user)

Training

There were widespread requests for the provision of training or capacity building for service users. There was agreement that service users should be supported to gain self-confidence, self-esteem and assertiveness in order to participate successfully in the development of their own (person-centred) service. Several people mentioned the importance of training in independent living skills. It was recognised that the transition from living in a residential home to living independently is frequently hampered by a lack of training and one-to-one support.

Many participants also suggested training for front-line workers. Some service users thought training for workers in 'how to empower' service users was necessary. Some managers thought that training in the core values of person-centred support would be helpful. Furthermore, it was recognised that many front-line workers felt disempowered within their service and not able to contribute effectively towards the improvement of the service. One manager spoke of the importance of '[re]affirmation for staff, to remind them, why and how it works (person-centred support)'.

One person felt strongly that facilitators of person-centred support should be given opportunities to train in counselling skills, in particular to build skills such as active listening and reflection.

Direct payments

There is growing national interest in schemes for self-directed support. One form these take are direct payments. Some service users talked about direct payments as an effective means of achieving person-centred support. They commented on the benefits they offered, specifically as a way of overcoming barriers of inflexibility in services. At the Get Together, knowledge among service users about how direct payments worked was varied, with many knowing very little. There certainly did not seem to be much familiarity with other approaches to self-directed support such as individual budgets. Some service users expressed an interest in finding out more about direct payments in the future after hearing about them from others.

> I am not confident about direct payments. I don't think I know enough about it.

> I don't know and I feel I should know a lot more and I should be going for direct payments myself.

It was clear from service users' comments that high-quality, accessible information about direct payments was necessary to enable people to make an informed choice. It was apparent that service users benefited from direct payment support services that enabled them to learn from their peers. People also talked about some of the problems because of the inadequate way in which direct payments might be implemented.

> Can I just add to that in another reflection. They have got direct payments in [this county] now so a person with a problem can apply for direct payments so they could do the personal care and pay someone then to do the other. So that needs rectifying. But a lot of people then are very hesitant to take that because they feel that at least with Social Services doing it and someone coming through that door, if they employ somebody and there is a breakdown in the system then they are left out in the blue yonder. So that is one of the barriers really. (Face-to-face worker)

Service users working together

Much of the discussion from participants about user involvement and its problems had been about the shortcomings of service users getting involved on their *own*. Some service users highlighted the difficulties in doing this: 'You cannot get anywhere just speaking on your own'.

Several service users, however, thought that there was strength in numbers and that this offered a way of overcoming such barriers. A group might be able to have an impact where an individual could not. They emphasised the value of *collective action*. They said:

> We can have more say by becoming stronger together.

> Getting together – passing the message from patients.

> If you bring people together, sometimes by joining together they can help each other better.

> We learn more from each other.

Given the difficulties of power imbalances between managers and service users, service users felt that it was easier to speak up and have the confidence to have

their say when they have the support of a group. This might be the case, for example, when having an input into the running of their service.

> We talk about different things like staff or any problems and everything. We have all the posh nobs in … and just put them on the spot and hope they answer.

Some people pointed out that it is often necessary to arrange training to support service users to participate in meetings like this. Two managers, who reported bad experiences, said that, if training and support were not available, the outcomes of involvement could be negative for individual service users and the service itself. One face-to-face worker talked about what was helpful for a group to work:

> [It's a matter of] group dynamics, it is mainly groups who have a dynamic group, so you have leaders and helpers and support within the group. If you have got that built in support mechanism then you can withdraw gracefully. You need to have a couple of core people who will take responsibility for running the group. It takes sometimes six months to develop that self-support and more and more they are taking control for what the ideas are, what they are doing, and making their own rules. And if you develop that from the outset, this is what we want, where we want to be, eventually down the road if they feel confident enough to take over.

There was agreement that support groups (or other groups set up for consultation purposes) must be open and truly supportive, putting service users at ease to encourage participation. Some service users said they might prefer to meet in a group solely with other service users, as this was likely to be a more supportive environment where they could feel more relaxed.

A large number of participants, including service users, workers and managers, stressed how useful they had found meeting in mixed groups at the Get Together event itself. Many said that they thought there should be similar meetings at a local level to discuss services. Some of the services already have meetings offering these mixed meetings, but many do not. One suggestion made was that such meetings could help to overcome barriers because they included people with different perspectives of services, so that these could be negotiated. They were seen to offer a useful forum for the sharing of ideas and could benefit from the views and experience of a wide variety of service stakeholders. One thing that seemed to be demonstrated by some of the feedback to the Get Together event was that people might be better able to go into mixed groups after first spending time together in groups on their own.

Support and building confidence

Managers and workers who had been involved in person-centred planning were very clear about its benefits.

> As they draw pictures they become very empowered by that experience.

> You can see the difference that makes to these people and seeing that they have the realisation that they can do something about it, is a very powerful experience.

A lack of confidence to speak out could be linked to perceptions of power imbalances.

> Sometimes people are in fear to speak up as they are afraid it will jeopardise their opportunities.

Therefore, people need confidence to get involved and to respond fully to person-centred support. We talked earlier how this might be enhanced by training. It could also be strengthened through advocacy and mutual support. Service staff talked about what they did and how it helped.

So first of all I think we engage them by working with them individually and quite often you will find people will tell you that due to external circumstances, they feel as though they have been let down or they feel like failures themselves. Sometimes they don't want to interact with other people at first but then what you find is as you get along and you build up confidence and self-esteem by accessing their needs, whatever they want to do, whatever they want to work on, and find that actually there is a common denominator at least between you and them, you can help them in some way, and they can actually move on and go on. (Face-to-face worker)

[B]ringing the ideas together and working together towards a shared experience. (Manager)

If I may, what you have said, it goes right across the piece – not just dealing with homeless people – right through the piece. There are people outside, whatever branch of care and medicine or whatever it is you are in, who feel outside and have great needs and don't know how to have those needs met. Yes, those who are trying to offer the needs can do all sorts of things, it is something to do with encouragement, affirmation, and you are probably going along that road and when you get to that point they will feel affirmed and empowered to come on board. Coming from, I am a carer in the older people's field, so that is my own particular experience, it is a lack of empowerment and the lack of desire quite often of the statutory bodies to date to go along with empowering people because they know that when they are empowered they will be a challenge maybe that they feel they can't meet. This is a barrier, to me it is a clear barrier. (Carer)

I think the by-product or even the actual point of [person-centred support], is to raise people's self esteem and awareness and I think confidence building is paramount if people want to change their lives and be master of their own lives. In our organisation we are increasingly giving people, or enabling people, to make choices for themselves and consequently some people are really beginning to believe in themselves and being able to feel as though they can integrate into mainstream society, and indeed make a contribution. (Face-to-face worker)

Sometimes people are afraid to speak out because they are in fear it will jeopardise their opportunities. (Service user)

What you need is to give somebody a small success and the confidence gained from that will give them confidence to take a risk in terms of gradually moving forward. (Face-to-face worker)

Small steps

Participants warned against seeing progress in terms of big reforms or changes. A large number of people said that we should not underestimate the significance of changes or outcomes that might seem modest or undramatic in themselves. This could mean a change both in someone's life and in the service or support on offer.

Actually something quite small is a big outcome in that person's life.

You can achieve a huge amount and it doesn't have to be giant leaps on the moon.

People stressed that recognition should be given to the small improvements and achievements made in response to an individual service user's goals. Small steps 'are noteworthy and rewarding' in themselves as well as in their contribution towards meeting an individual goal. What was important was not necessarily the scale of change (although what some people might see as small, others might regard as big), but rather that it was consistent with person-centred support.

Core values

This draws us back to the issue of values. What became clear from participants' comments was that they did not see person-centred support as about operating services in a technically different way. Rather, they saw it as an approach to support informed by the kind of values and principles which they identified and which we reported in the second chapter of this report.

Thus many people said that person-centred support was about a way of thinking. It is about core values in a service. This may require transformational change in an organisation, 'not tinkering' with what already exists. Some participants said that it was vital to give it priority and stick with it, saying it should be included in all 'day to day plans'. Managers said:

> Person-centred support is about core values, not hints or tips. There are no easy short-cuts. You have to adopt the correct core values.

> It's an organic process. It can take years to root.

There was a feeling that many face-to-face workers were jaded from a pattern of development in social care based on experiencing constant change, reflected in a series of endless new initiatives. Person-centred support could be experienced as just one more of these. This had resulted in some workers feeling that providing person-centred support was merely an addition to the overall level of their workload, rather than a genuine new departure. Face-to-face workers argued against this, saying:

> It's not another job, it's *the* job. Person-centred support is not *another thing* that you have got to do. It *is what* you have got to do.

> It is more than just having a whole manual of different tools to use; it is about thinking in a different way.

For workers like these, person-centred support was more than a 'buzz term' or 'the latest thing'. It was a central principle that should underpin practice, policy and thinking.

Managers emphasised the importance of *how* changes are presented to workers and, in turn, how they try to approach person-centred support to encourage people to own it.

I think some of it is about training issues, and I think it is not about person-centred care being *an approach that we use*, it would actually be *the way that we work,* and the way that we work with staff from roots level upwards, and actually instil that from the beginning. Because if that is the only way you work, then you are not battling against other processes.

I think if the project worker, as a manager, is really enthusiastic and pro person-centred planning as an approach, then it happens really quickly. But if the project worker has any concerns or hang ups of their own about it then they find a million excuses why it is not going to work in their stream or with their clients. [Their attitude will be] 'My clients won't like this' or 'They won't want to do it', or 'I haven't got time, there is no way I have time to do these bits of planning'.

Those workers who had been working using person-centred planning said:

The more you do it the easier it becomes.

Once the principles and PCP [person-centred planning] tool were used … it actually ended up making the key worker role much easier.

One service user summed up what this meant to them.

When you spoke, as soon as you opened your mouth and started talking about how you work, I could understand straightaway where you are coming from. You are not looking for a badge, you just want people to understand this is the way we do things. Does that make sense?

Differences in perspective

There did not seem to be any major difference in perspective between the three key stakeholder groups: service users, face-to-face practitioners and managers with regard to overcoming barriers. However, service users did emphasise the advantages of being able to meet together in groups and tackle problems collectively.

All three constituencies identified ways of overcoming barriers and advancing person-centred support through:

- developing trust;

- pursuing a positive approach;

- sharing good practice;

- promoting person-centred support;

- training for person-centred support.

All cited improving communication, but it was service users who had specific suggestions to offer. All stakeholders cited participation, but it tended to be workers and managers who gave examples. Managers and staff spoke about support and building confidence and the importance of small steps as well as the importance of core values.

5 Discussion and recommendations

This final chapter considers some of the broader findings emerging from this report, their implications for future policy and practice, and offers some recommendations based on them.

Person-centred support is still a new idea in policy-making terms, even though there is a long history of efforts to tailor support to the individual rather than forcing her or him to fit into existing service systems. This is reflected in the overall pattern of services that social care service users receive. There are currently more than one million social care service users, and 500,000 still live in residential institutions. Only about 50,000 receive direct payments, although they have now been in existence in one form or another for more than ten years. Only about 2,000 service users are estimated to be accessing individual budgets at the time of writing, although these are now being seen as an important precedent for the future.

Key issues emerging

This report includes the views of a very wide range of service users, from a variety of services, in many parts of the country, with very varied experience of 'person-centred support'. For some, it was a familiar idea. For others, it was something they might be hearing about for the first time when they met with others for this project. There are several general points to make about what people had to say.

- There was great consistency in what people said about person-centred support. This was true both among and between different stakeholder groups: service users, face-to-face practitioners and managers.

- Person-centred support seems to be a helpful umbrella term for all three stakeholder groups to describe a range of approaches to services and support which aim to be user, rather than service led.

- Service users, face-to-face practitioners and managers spoke about first-hand experiences of barriers to services being person-centred.

- Generally, people were positive about person-centred support. They saw it as a helpful way forward for health, social care and related provision.

- While some of the barriers identified (for example, inadequate resources) are well known and have frequently been brought to the attention of policy-makers, others were more subtle and complex and the clearer picture we now have of the obstacles that people feel are hindering them should help make it easier to negotiate them.

- While participants did not minimise the barriers in the way of person-centred support, there was also optimism in their approach and many suggestions for how to take work forward successfully. There was no suggestion that we had to wait for global change (for example an age of adequate funding) before we could take positive steps forward.

Service users' comments were also closely consistent with views reported in other related studies. Thus many of the responses from participants about barriers to person-centred support corresponded to those reported in other research with service users about problems with services (Beresford, *et al.*, 2005; Beresford and Forrest, 2007; Branfield, *et al.*, 2005, 2007; Harding and Beresford, 1996; Morris, 1993; Shaping Our Lives, *et al.*, 2003; Turner, 1997, 1998). Significantly, these findings have been reported over a number of years, suggesting that service users are still experiencing the same problems as they did in the past and that there have not been large-scale or universal improvements over this period.

Participants offered cogent answers to three key questions which we sought to explore:

- What does 'person-centred support' really mean?

- What are the main barriers to such person-centred support?

- How can these barriers can be overcome?

As we saw in Chapter 2, put together, their comments provided an effective and useful working definition of person-centred support, which identified what people saw as its important elements, offering a benchmark by which services could judge themselves.

There also seemed to be agreement among different participants about a number of key issues relating to person-centred support. These included:

- Their belief in the importance of core values as the basis for person-centred support. This meant that they were suspicious of any ideas that there were likely to be techniques or shortcuts to achieving meaningful person-centred support or towards overcoming barriers in the way of it.

- A distinction emerged from what people said between person-centred *planning* and person-centred support. Some people had been trained in or experienced first-hand various person-centred planning techniques. Others saw person-centred working as a less defined overall approach towards best practice in the provision of services. The two should not be seen as the same. Person-centred planning is probably the best-known expression of person-centred support. It represents a particular approach to doing it, rather than the only way of doing it. While person-centred planning has gained particular prominence, it is probably most helpfully seen as one possible way of taking forward person-centred support, rather than the only way.

- In person-centred support, the process involved is likely to be as important as the stated or intended outcome. That is to say, how things are done is likely to be as important as the objectives that are envisaged (and have a strong bearing on the likelihood of their being achieved). Service users, in discussions of user-defined outcomes, make the same point. (Turner, 1997, 1998). Thus attention needs to be paid to both these interrelated but also distinct elements in person-centred support.

- Many managers and practitioners expressed concern that person-centred support might result in targets that were 'unrealistic' because services could not provide or support what had been identified by the service user. It may be that, at a time when eligibility criteria for services are increasingly restrictive, services feel unable to offer more than a basic service. However, managers and practitioners might benefit from drawing a distinction between two different roles. One role is as service provider (for example of a residential home), while another is in supporting a service user to plan. Therefore, services do not have to provide for a person 'to fly to the moon', but they should be assisting service users to think about how to work towards their goals and benefit from the process. By working towards a goal, a person is building a network of contacts, making choices, learning new skills and becoming more independent.

- This highlights the issue raised by both service users and service providers that service users need to be supported to be in a position to respond to and take forward the opportunities person-centred support may offer. Support, advocacy, capacity building and so on need to be seen as inherent elements of person-

centred support. It cannot be seen as something that merely *acts on* service users. They need to be in a position to be active agents in the process.

- Service users placed an emphasis on involvement and being part of a service user controlled group or organisation as a key element towards making person-centred support work. Such involvement also offers a key means of accessing the information, capacity building and support which all stakeholders see as essential for person-centred support.

The Get Together day offered a unique opportunity to bring together service users, face-to-face practitioners and managers; for them to share their views and for us to generate new broad-based knowledge about person-centred support. But the Standards We Expect project, which the event formed a part of, is a *development* as well as a research project (for more information about the project, see Appendix 1).

So as well as the day having a part to play in adding to the evidence base about person-centred support, it was also intended, from the views and ideas it generated, to help shape the agenda for the rest of the project and to take forward work on person-centred support in the network of eight core and twelve further sites. We wanted to see what key issues emerged for participants when they came together and to combine this with what they said they wanted from the project when we spoke to them at the individual partner sites. Three key activities with partner sites and the broader network of participating organisations emerged from this to be taken forward:

- customised development work requested by and agreed with specific sites linked to the overall agreed goals of the project;

- a major programme of training and capacity building in partner sites with each of the three key stakeholder groups; this included:
  – a series of 'Making a Change' workshops with service users to build capacity and increase their involvement;
  – a similar programme of training with face-to-face practitioners to support them to have confidence to contribute to developments in the service they provide and to work in empowering ways with service users to take forward person-centred support;
  – a learning workshop bringing together managers from the partner sites to share knowledge and advance policy and practice in developing person-centred support.

- a second Get Together event towards the end of the Standards We Expect project, providing an opportunity to exchange and share progress and ideas in the project on developing person-centred support.

Thus the Get Together event has been more than a valuable chance to hear what a diverse range of service users, face-to-face practitioners and managers have to say about person-centred support and for that to become part of the wider evidence base. It has also made it possible for people's views to be fed into the project to make a genuine difference by influencing what happens next. We shall be reporting these findings in the final outputs and materials from the project.

Recommendations

- The initiative reported here highlights the value of involving the three key perspectives of service users, face-to-face practitioners and managers in exploring how best to take forward person-centred support. All three stakeholders should be routinely and centrally included in further efforts to take forward person-centred support.

- Outcomes measurement which focuses on 'hard' data meeting managerialist imperatives, such as performance indicators, is not enabling service users or staff to demonstrate adequately or appropriately the value of person-centred support/ services.

- The growing interest developing in 'personalisation' and person-centred support emphasises the need for more work to be done on evaluating its effectiveness. This report suggests that it will be helpful to include both service use and practitioner perspectives at the heart of such evaluation.

- This report highlights that a wide range of different approaches to person-centred support are developing. It is important that such developments are systematically and independently evaluated to identify their various strengths and weaknesses and routes to improving them.

- Participants in this project emphasised the importance of information for advancing person-centred support. More work needs to be done to make existing information about person-centred support more readily available to practitioners and service providers and to ensure that it is accessible to a wide range of service users.

- 'Carers' or family members were identified as a potential barrier to person-centred support because their own concerns and needs could get in the way of those of service users' and because of the lack of support available to them. More work needs to be done to support carers to play a positive role in advancing person-centred support.

- Participants valued the opportunity to meet with different stakeholders and to think and work through their different interests in person-centred support together. This suggests that it is likely to be helpful to encourage meetings and forums in and between organisations and service providers to take person-centred support forward, which make it possible for the 'different layers' of stakeholders – managers, practitioners, service users and others – to meet, share and talk about their different perspectives and common interests.

- Given the growing interest among policy-makers in new approaches to self-directed support, such as individual budgets, it is likely to be of particular help both for these to be subjected to independent evaluation and for findings to be made as widely available and accessible as possible.

- User-controlled services are likely to have a particularly helpful role to play in taking forward person-centred approaches to support because of the high value and trust which service users place in them (Barnes and Mercer, 2006).

- Concerns about 'risk' to both service users and staff are constraining person-centred support by restricting rights and choices. Issues of 'risk' need to be subjected to much more rigorous evaluation in relation to person-centred support values.

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Appendix 1 The Standards We Expect project: participatory approaches to developing person-centred support

This is a two-year research and development project focusing on person-centred support which is supported by the Joseph Rowntree Foundation (www.jrf.org.uk).

The project team

The project is being undertaken by a partnership of four organisations, led by Shaping Our Lives, the independent, national, service user organisation and network (www.shapingourlives.org.uk) (Fran Branfield and Michael Turner). The other organisations are: Values Into Action (www.viauk.org) (Kiran Dattani Pitt and Catherine Bewley); the Centre for Social Action, De Montfort University (www.dmu.ac.uk/dmucsa) (Jennie Fleming) and the Centre for Citizen Participation, Brunel University (www.brunel.ac.uk/about/acad/health/healthres/researchareas/cc/) (Peter Beresford).

Partners also include a social work practitioner (Suzy Croft), a university lecturer (Karen Postle), two consultants from the Race Equality Foundation (Jabeer Butt and Ronny Flynn) and a person with experience of working with older people in reference to person-centred support (Charles Patmore). The partnership employs a full-time project worker (Michael Glynn).

Partners have relevant experience in policy and practice change at grassroots and national levels, involving diverse stakeholders, undertaking evaluation and have respect and trust among key stakeholders. (To find out more about the partnership organisations please visit our websites.)

Project aims

The aim of the Standards We Expect project is to encourage and guide the development of person-centred support in eight local areas, working with partners in each. The aim is to enable service users to play a much greater role in shaping the support they receive to meet their rights and needs. In addition to the eight partner

sites, there is a broader network of twelve services who want to share learning and take forward person-centred support.

Particular attention is being paid to supporting the involvement of service users and face-to-face practitioners, groups which continue to face particular exclusions in this context.

The approach to this project is based on enabling stakeholders to engage in the process of change through identifying existing forums and developing a range of new ones, particularly to ensure the involvement of practitioners and service users, enabling stakeholders to develop, share and negotiate their perspectives and contribute on as equal terms as possible to the change process. This involves the provision of support, information and training by the project team.

The project aims to identify criteria for person-centred support with practitioners, service users and managers, as well as exploring barriers that are impeding it and ways in which these barriers can be overcome.

The project will analyse and evaluate both the activities and responses of partners and the way the project itself works. There will be regular feedback to partners and the wider network of a further twelve organisations, as a basis for change, drawing on qualitative and user-led approaches to evaluation.

Appendix 2 The Get Together day programme

The Standards We Expect project

Get Together

3rd November 2006

Venue   The Resource Centre, 356 Holloway Road, London

Time   10.30 am to 3.30 pm

Welcome to our Get Together!

Today is very important for our project. We hope you will have an enjoyable and productive day.

The purpose of the day is

- for people from all our partner sites to meet;
- for service users, front-line workers and managers to meet;
- for everyone to have their say in whatever way most suits them;
- for us to talk about what 'person-centred support' means;
- for us to talk about ways of overcoming the barriers
  to person-centred support.
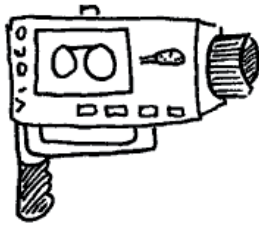
During the day please make use of our VIDEO ROOM. This is available during registration and at breaks and lunchtime. It is a chance to record your own views. You can also add your thoughts and comments to our flipcharts in the Exhibition Hall throughout the day.

Agenda

9.45am – 10.30am Arrival and Registration

- Refreshments and registration (Exhibition Hall)
- Video room
- Stalls and information
- Chance to chat with others

10.30am – 11.00am Welcome (main room)

- Housekeeping and Ground Rules
- What is today about?
- Introduction to the project
- Getting to know each other

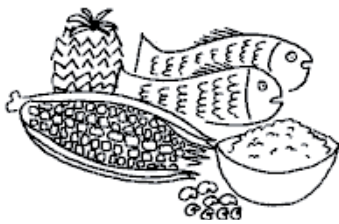**11.10am – 12.30pm** Discussion Group (breakout rooms)

We will split into small mixed groups and discuss the following:

- What do we mean by person-centred support?
- How person-centred are services in your area?
- In what ways are service users and front-line workers involved?
- What are the barriers to person-centred support?
- What barriers have you come across in your area?

12.30pm – 12.50pm Feedback (main room)

We will come back into the main room and the discussion group leaders will give brief feedback from their groups.

12.50pm – 1.50pm Lunch

- Lunch served in the Exhibition Hall. Extra chairs and tables in the Conference Hall
- Video room

1.50pm – 2.00pm Entertainment spot: Raz, performance poet and singer/songwriter (main room)

2.00pm – 3.00pm Discussion Group (breakout rooms)

We will split up into small groups of either service users, frontline workers or managers, and discuss the following:

- In your experience, what are the main barriers to person-centred support?
- How can we overcome the barriers?
- What has and hasn't worked in your own area and why?
- How can service users and front-line workers be more involved?
- What ideas do you have for overcoming barriers in the future?
- How do you think the Standards We Expect project can help overcoming barriers?

3.00pm – 3.30pm Plenary Session and Closing remarks (main room)

- We will come back into the main room and give brief feedback from the second discussion group.
- We will look back at key points made during the day.
- Anne Harrop from the Joseph Rowntree Foundation will speak about her hopes for the project.
- We will talk about what happens next in the project.

3.30pm – 4.00pm Opportunity for Networking (exhibition hall and conference hall) and Refreshments

4.00pm Close

Appendix 3 Feedback form from the Get Together event

Evaluation Form for the Standards We Expect Project Get Together, 3 November 2006

Please rate the following parts of the day:

	Very Good	Good	OK	Poor
Overall event				
Discussion groups				
The venue				
Organisation and support				
Lunch				

What did you like most about the day?

Is there anything else you would like to tell us about the day?

What would you most like the Standards We Expect project to do in the future?

Appendix 4 Resource list

General disability-related information

www.disabilityalliance.org   Disability Alliance (DA), publishers of the *Disability Rights Handbook*, is regarded as the leading authority on social security benefits for disabled people. You can use this site to find regularly updated information about benefits, tax credits and community care as well as disability benefits related campaigns

www.disabilitynow.org.uk   Website from the popular *Disability Now* newspaper. The paper is available free of charge to disabled people

www.direct.gov.uk/en/DisabledPeople: Government website providing information about housing, employment, education, benefits, transport etc.

www.radar.org.uk   RADAR is a national network of disability organisations and disabled people. They represent members by fast-tracking their opinions and concerns to policy-makers and legislators in Westminster and Whitehall, and launching their own campaigns to promote equality for all disabled people

www.scie.org.uk   The Social Care Institute of Excellence's (SCIE) aim is to improve the experience of people who use social care by developing and promoting knowledge about good practice in the sector. You can read lots of reports they have written

www.adviceguide.org.uk   Citizens Advice Bureau The Advice guide website is the main public information service of Citizens Advice, providing people with round-the-clock access to CAB information on their rights, including benefits, housing and employment, and on debt, consumer and legal issues

www.after16.org.uk   Information aimed at disabled teenagers

www.abilitynet.co.uk   Ability Net is a national charity helping disabled adults and children use computers and the Internet by adapting and adjusting their technology

Participation

www.shapingourlives.org.uk   Shaping Our Lives National User Network is an independent user-controlled organisation. It aims to support the development of local user involvement aiming to deliver better outcomes for service users

www.bcodp.org.uk   The UK Disabled People's Council (formerly the British Council of Disabled People). They were set up in 1981 by disabled people to promote full equality and participation in UK society, and now represent some 70 groups run by disabled people in the UK at national level

www.dialuk.info   DIAL (Disability Information and Advice Line) UK, a national organisation for a network of approximately 130 local services run by and for disabled people. Site can be used to find details of your local DIAL

www.involve.org.uk   Involve promotes public involvement in NHS, public health and social care research. You can look at various publications and reports on the website

Barnes, C., and Mercer, G. (2006) *Independent Futures: Creating User-led Disability Services in a Disabling Society*. Bristol: The Policy Press

Begum, N. (2006) *Doing it for Themselves: Participation and Black and Minority Ethnic Service Users*. Bristol: The Policy Press

Beresford, P. (2002) 'User involvement in research and evaluation: liberation or regulation?', *Social Policy And Society*, Vol. 1, No. 2, pp. 93–103

Beresford, P., Croft, S. (1993) *Citizen Involvement: A Practical Guide For Change*. Basingstoke: Palgrave Macmillan

Kemshall, H. and Littlechild, R. (eds) (2000) *User Involvement and Participation in Social Care*. London: Jessica Kingsley

Improving consultation/involvement

Branfield, F. and Beresford (2006) *Making User Involvement Work*. York: Joseph Rowntree Foundation

Carter, T., Beresford, P. (2000) *Age and Change: Models of Involvement for Older People*. York: York Publishing Services with Joseph Rowntree Foundation

Hanley, B. (2005) *Research as Empowerment: Report of a Series of Seminars Organised by the Toronto Group.* York: Joseph Rowntree Foundation

Shaping Our Lives (2003) *Guidelines for Making Events Accessible (Including Ground Rules).* Available at www.shapingourlives.org.uk

Payments to service users

Care Services Improvement Partnership (2006) *Reward and Recognition: the Principles and Practice of Service User Payment and Reimbursement in Health and Social Care – a Guide Service Providers, Service Users and Carers.* London: Department of Health

Turner, M., Beresford, P. (2005) *Contributing on Equal Terms: Service User Involvement and the Benefits System.* Bristol: The Policy Press

Person-centred planning

www.circlesnetwork.org.uk   Circles Network is a national voluntary organisation based around the key principles of inclusion and person-centred planning approaches. Includes resources and details of training

www.paradigm-uk.org   Paradigm provides a range of tailor-made supports, including consultancy, training, conferences, publications and information; helping people, communities and services build an inclusive future. The website is a useful source of information and writing about person-centred planning

Dowling, S., Manthorpe, J. and Cowley, S., in association with Sarah King, Vicki Raymond, Wendy Perez and Pauline Weinstein (2006) *Person-centred Planning in Social Care.* York: Joseph Rowntree Foundation

Helen Sanderson Associates, *Listen to Me Workbook.* Available from www.helensandersonassociates.co.uk

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O'Brien, J., Lyle O'Brien, C. (eds) (1998) *A Little Book About Person-centred Planning.* Toronto: Inclusion Press

Robertson, J., *et al.* (2005), *The Impact of Person-centred Planning*. Lancaster: Institute for Health Research

Sanderson, H. and Webb, T. (2002) *What is Person-centred Planning?* Available from www.helensandersonassociates.co.uk

Outcome measurement

Balloch, S., Beresford, P., Evans, C., Harding, T., Heidensohn, M., Turner, M. (1998) 'Advocacy, empowerment and the development of user-led outcomes', in Craig, Y.C. (ed.) *Advocacy, Counselling And Mediation In Casework*. London: Jessica Kingsley, pp. 226–236

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Raynes, N. (2001) *Getting Older People's Views on Quality Home Care Services*; full report Raynes, N. *Quality at Home for Older People: Involving Service Users in Defining Home Care Specifications.* Bristol: The Policy Press. http://www.jrf.org.uk/knowledge/findings/socialcare/pdf/611.pdf

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Turner, M., Beresford, P. (2005) *User Controlled Research, Its Meanings and Potential.* Shaping Our Lives and the Centre for Citizen Participation, Brunel University

Turner, M. (1997) *Shaping Our Lives: Interim Report*, October. London: Shaping Our Lives, National Institute for Social Work

Turner, M. (1998) *Shaping Our Lives: Project Report*, October. London: Shaping Our Lives, National Institute for Social Work

Direct payments

www.ncil.org.uk   The National Centre for Independent Living (NCIL) is a not-for-profit company controlled by disabled people. NCIL is the national organisation providing information, training, expertise and policy development on all aspects of direct payments and independent living. Their aim is to enable disabled people to have self-determination, choice and control, equal access to economic, social and cultural life

www.ilf.org.uk   The Independent Living Funds (ILF) are two funds set up and financed by UK central government. The funds were set up as a national resource dedicated to the financial support of disabled people, enabling them to choose to live in the community rather than in residential care

Breaking Barriers: A Direct Payments video, produced by Equalities, aimed at disabled people from the black and minority ethnic communities. Available via NCIL

Everything You Need to Know About Getting and Using Direct Payments: This NCIL publication includes references to the new Direct Payments Guidance, contains more

examples of administrative paperwork, such as job application forms and contracts of employment. The book also contains examples, where a direct payment can be used to assist in real life situations

Clark, H., Gough, H., Macfarlane, A. (2004) *'It Pays Dividends': Direct Payments and Older People*. Bristol: The Policy Press with Joseph Rowntree Foundation

Leece, J. and Bornat, J. (eds) (2006) *Developments in Direct Payments*. Bristol: The Policy Press

Vasey, S. (2000) *The Rough Guide to Managing Personal Assistants*. Available at http://www.independentliving.org/docs6/vasey2000.html. If you are a disabled person and about to start receiving a Direct Payment to employ your own personal assistants (PAs), this book aims to give you a flavour of what it is like: the joys and the challenges. The book covers recruitment, managing, using PAs in social situations and at work, and dealing with problems

Vasey, S. *Direct Payments: A Beginner's Guide*, National Centre for Independent Living: A 30-minute video which covers the essential aspects of managing a PA set up, including recruitment, supervision and contracts

The following books are all available from Values Into Action:

Beamer, S and Brookes, M. (2001) *It's Your Choice.* An interactive and accessible workbook telling people about their right to choice and control

Bewley, C and Holman, A. (2002) *Pointers to Control*, 2nd edition. Information on important issues related to direct payments: consent, control, money management, employment and eligibility

Bewley, C and McCulloch, L. (2004) *Helping Ourselves.* Investigation into the importance, availability and quality of peer support for people with learning difficulties who use, or want to use, direct payments

Holman, A. (1998) *Make Your Move*. An award-winning video made by and for people with learning difficulties about living in your own home and controlling your own support

Risk, heath and safety

Concerning flexibility, inflexibility and health and safety practices

Alaszewski, H., Alaszewski, A. (2005) 'Person-centred planning and risk', in Cambridge, P., Carnaby, S. (eds) *Person-centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Denney, D. (2005) *Risk and Society*. London: Sage

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