

Person-centred support: What service users and practitioners say

July 2008

This summary tells you about the Standards We Expect project.

Introduction

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, personalisation, aims to support people to make choices and to be included. It goes under many different names, including 'independent living', 'person-centred support' 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 study 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.

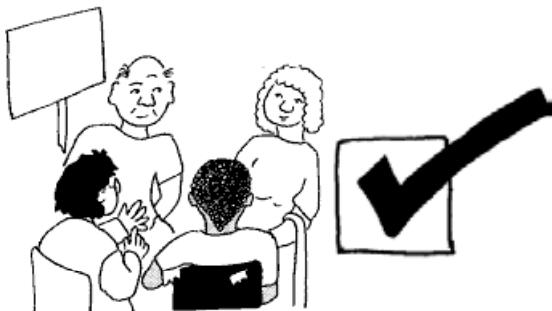
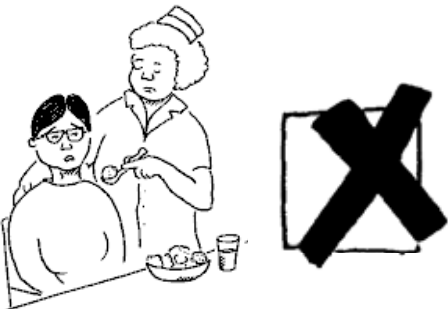
'Personalisation' of public services has become fashionable for politicians, policy-makers and providers. This research is a timely reminder that service users have long been arguing for, and designing, person-centred services. Change will only happen if services are shaped by the people who rely on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

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 support. 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; and
- 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; and
- 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 overcome?

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; and
- 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; and
- 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

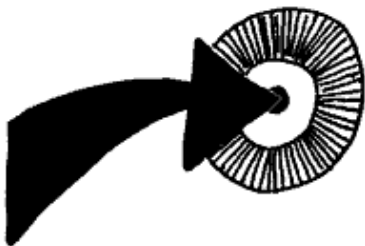
Service users think person-centred support has a lot to do with choice and control:



- 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; and
- having the chance to learn about making decisions.

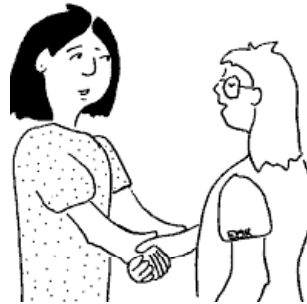
Setting goals

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'.



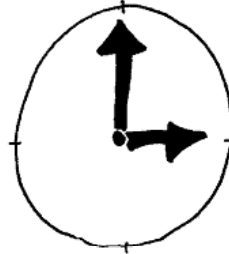
Lack of information

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.



Staff time and approach

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



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.



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.



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.



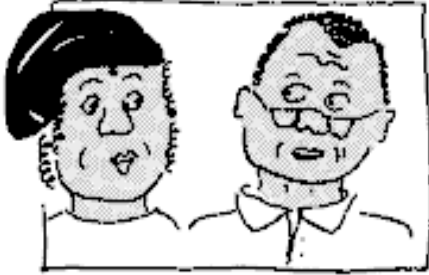
Communication

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

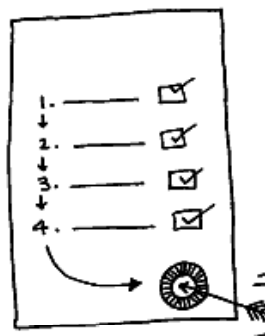
Some service users spend a lot of time going to meetings and giving their views to help services become better. But they can feel very frustrated when services do not change. User involvement is a problem when:

- people are not supported to get involved;
- people are not given feedback about what happens next; and
- 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; and
- 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 support.



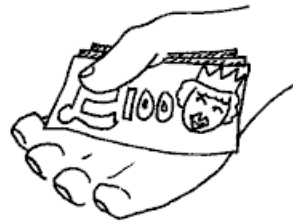
Training

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

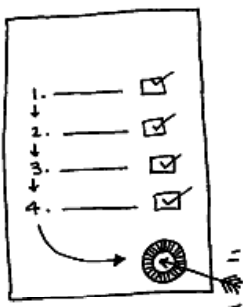
What seem to be the small steps that people make towards their goals are very important.



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 summary talks about and what the Standards We Expect project thinks should happen next.

These are the main things that this summary 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 need to be more chances for people to get together to talk about person-centred support.



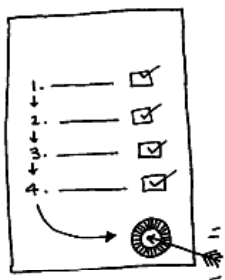
- People think person-centred support is a good thing. Even though there are difficulties, people feel positive about it. We do not have to wait for big changes to make it happen. We can do it now.



- 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.



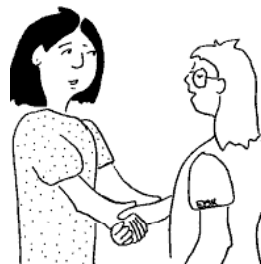
- There are no short-cuts to doing person-centred support right.



- 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').

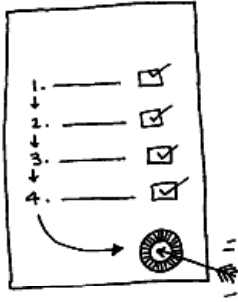


- Service users said that being involved in decisions about services is very important. User-controlled organisations are very important for person-centred support.



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.



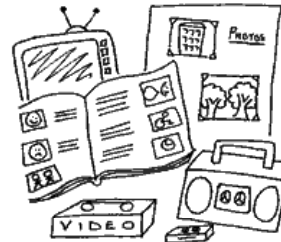
- 3 Any research or study about person-centred support must include the views of service users and staff.



- 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.



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



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



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



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.



What happens next?

The Standards We Expect project is doing follow-up work on the project:

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



About the Standards We Expect project: participatory approaches to developing person-centred support

This is a three-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 (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 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.



For further information

Person-centred support: What service users and practitioners say is published by the Joseph Rowntree Foundation. It is available as a free download from www.jrf.org.uk.

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