

Person-Centred Support: a guide for service users



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

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

The Standards We Expect Consortium



Written, edited and produced by
The Standards We Expect Project

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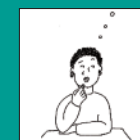
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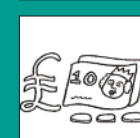
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Foreword

There has been a revolution in the way we think about social care in the United Kingdom. It is called Personalisation, and at its heart is the idea that the person knows best what kind of service they require. Furthermore, they can design it to meet their personal circumstances.

This change presents a considerable challenge to the established services in social care. However, as with all such Government policies that require a lot of change, it is the professionals and officials who receive most of the advice and support about how to change. All too often, the most important people, the users of those services are forgotten or poorly informed about what is actually going on.

This is why 'Person-Centred Support: a guide for service users' is very important. It was produced after talking to many users of services about what they expect from a new social care service that put their wishes and concerns first.

This guide will help you obtain useful information and practical advice about the services you use. Its purpose is to provide useful information about person-centred support. It will help complete the picture for users about what Personalisation will mean for them. What is more important, it will also help people to act on their new rights as users of social care services.

This is not the only thing that it will offer. It will talk about disabled people's rights, the importance of Social Model Disability, and, crucially, Human Rights and diversity.

The guide's key message is that person-centred services are a right for all of us, whatever our background or ethnicity.

I am aware that many people have contributed to this guide. Their insights and views helped shape what has become a very valuable handbook.

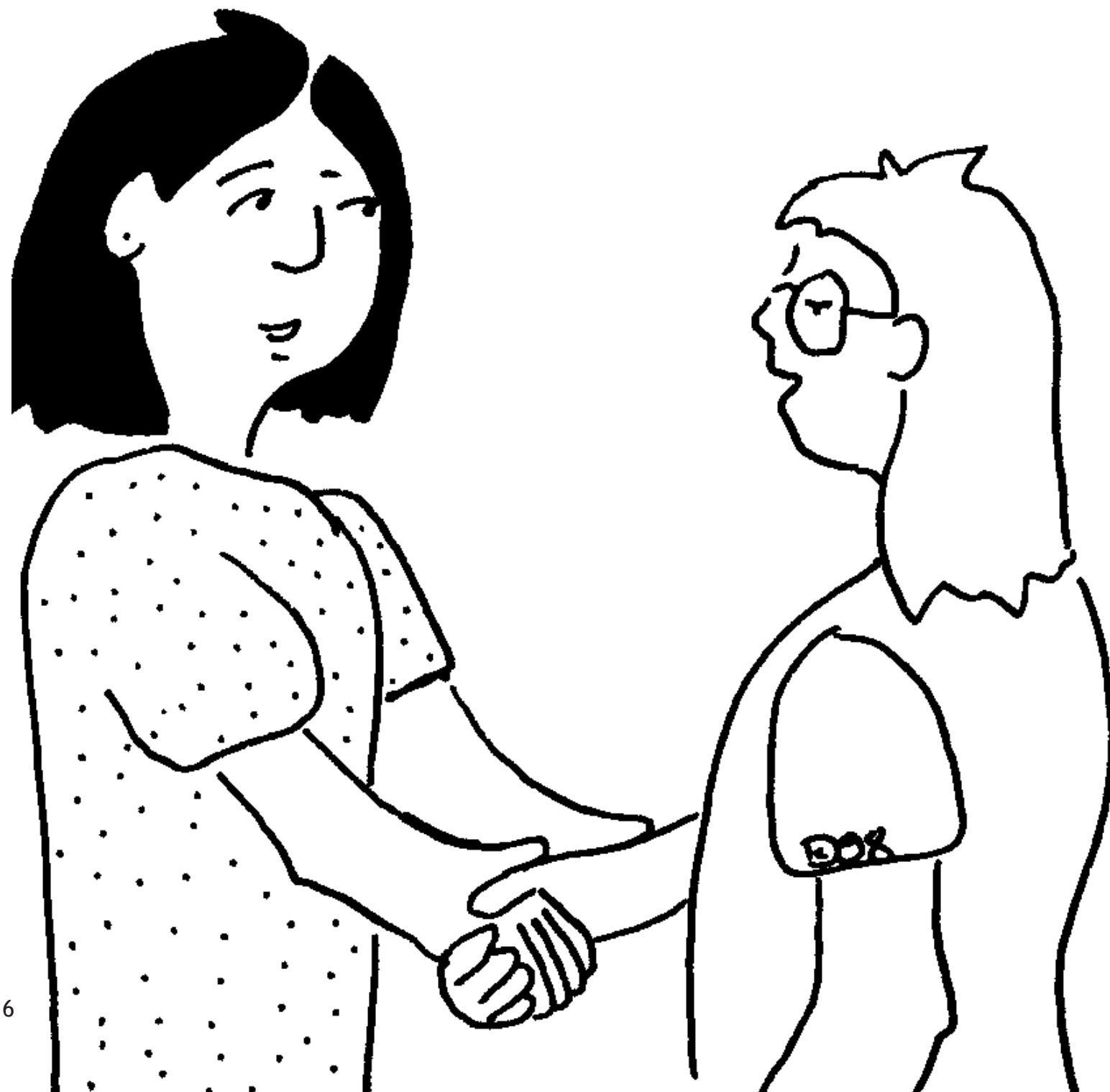
I am confident that it will help many people obtain the best solution for themselves in this rapidly changing social care world.

Ossie Stewart Independent Disability Consultant



What is person-centred support?

Person-centred support means you are at the centre of your service. Services should work with you to help you live your life in the way you want.



Our project found that there are eight important things about person-centred support. They are:



1. Choice and control

This means being in charge of your life and having support to make decisions.



2. Setting goals

This means deciding what you want to do or change in your life.



3. Good relationships

It is important to have good relationships with family members, friends, people who work with you and other people. They help make things happen and help you to feel part of your community.



4. Listening

Services and the people who work for services need to listen to you so person centred support happens.



5. Information

Having the right information you need in the way you want it is very important. It can be difficult to make good choices without it.



6. Being positive

Being positive is important. It helps you feel more in control of your life. You can usually make better choices when you feel positive.



7. Learning

Person centred support helps you try new things and learn new skills.



8. Flexibility

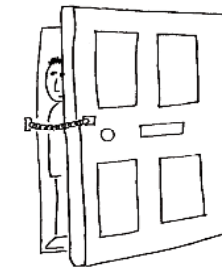
Person centred support is about services being flexible enough to fit your life. It is not about 'one-size fits all' or giving everyone the same service.

The social model of disability

Over the last 30 years, disabled people have come together to fight for rights and equality.



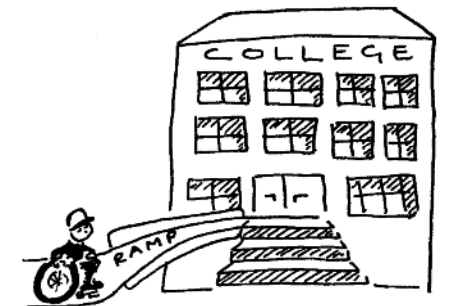
Disabled people have started their own organisations to help each other and campaign for change.



An important part of this campaign is an idea called the social model of disability. This is sometimes called the barriers approach to disability.

This idea looks at the way society makes disabled people's lives difficult. This means things like:

- buildings that are difficult to get into
- treating people unfairly at school, college or work
- people not having the right services and support.



Looking at disability in this way challenges the idea that disability is about what people cannot do because of their medical problems or conditions.

The social model of disability is about rights and equality. It is also sometimes called the equalities approach because it's about having the same chances in life as everyone else.



The social model of disability is about what society, organisations and people need to do to make equal chances happen.

The Project thinks that person centred services are about helping people to live their lives as they want to. People need rights and equality to do this. They also need choice and control over their support.



Helping each other

It can be really good to meet other service users to share stories, experiences, ideas and action.



We can make things change better and faster if we work together.
We are more powerful together.



There are several ways to find out how to meet other service users where you live.

One good way is to use the SOLNET website run by Shaping Our Lives.

This website lists over 200 organisations of people who use services. You can find your local service user organisation and get involved.

The website also has information about events and opportunities you can get involved in.

www.solnetwork.org.uk



Your rights

This section tells you about some important rights you have in law.



Your right to make decisions

There is a law called the Mental Capacity Act 2005.

This law is all about making choices and decisions about your life. This could be about small daily choices – like what to wear and what to eat – to bigger choices – like where to live. The law says:

- You have a right to make your own choices and decisions.
- You have the right to make decisions even if other people disagree with you.
- Other people have to support you as much as possible to make your own choices.
- No one should think you can't make decisions because of:
 - your age
 - how you look
 - how you behave
 - if you are disabled
 - if you can't make big decisions
 - if you couldn't make a decision in the past.



Equality and diversity

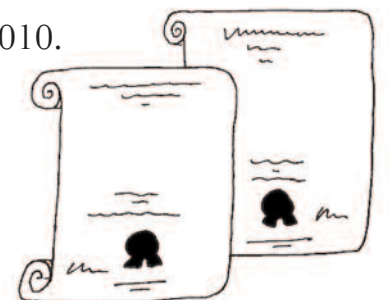
Equality means all people have equal rights and equal opportunities.

Diversity means we are happy that people are different in lots of different ways. We value our differences.

Equality Act 2010

We have a new law called the Equality Act. It started in October 2010.

The Equality Act says that public organisations – like services – have to take action to make things equal for the people who work for them and the people who use their services.



Public organisations must:

1. Make sure their service does not discriminate, harass or pick on people who use or work in the service.

Discriminate means to treat someone differently in a bad way because of who they are. Harass means being horrible to someone because of who they are.
2. Take positive action so there is more equal opportunity for all service users and workers.
3. Do their best to help everyone get on better.

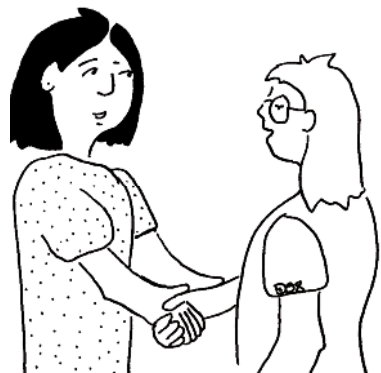
The Equality Act says that people must not be discriminated against because of their:

- Age
- Disability
- Gender
- Gender reassignment (transgendered people)
- Marriage or civil partnership
- Pregnancy or maternity
- Race
- Religion and belief
- Sexual orientation.



Equality law says that employers and organisations that provide any type of goods or services are breaking the law if they treat disabled people in a different way to other people because of their impairment or disability. Services must make 'reasonable adjustments' to make something accessible or easier for you to use. This might cover things like:

- Putting in a ramp to make a building accessible
- Providing disability awareness training for staff
- Providing an interpreter for deaf people.



Your right to services and support

Under the Community Care Act of 1990 you have a legal right to have an assessment to see if you need services. If the assessment says you need a service and you fit your local authority's eligibility criteria, then you have a legal right to get a service.

Getting help

If you think you are being treated unfairly because of who you are you can:

- Tell your staff or a manager
- Use the service complaints procedure
- Talk to your local rights organisations
- Tell your MP or local counsellor
- Contact the Equality and Human Rights Commission (address at the end of this report).



Human Rights Act 1998

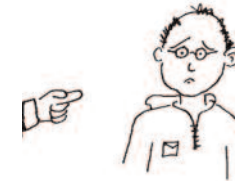
There is a law called the Human Rights Act. This law gives everyone in the country rights as human beings:



ARTICLE 2

The right to life

You have the right not to be killed and to have your life protected. This covers protection from hate crime.



ARTICLE 3

The right not to be treated in cruel, inhuman or degrading ways

Services and support staff must work with you in ways that respect your dignity and humanity.



ARTICLE 5

The right to freedom and to be safe

Services should not unlawfully restrict your freedom and should act against bullying or hate crime.



ARTICLE 8

The right to private and family life

You have the right to live in the same way as everyone else in your community. This is an important right for disabled people who are sometimes only offered housing and services with groups of other disabled people. It is also an important right about getting married, getting support to be a parent and for taking part in your local community.



ARTICLE 9

The right to have a religion and to have your own ideas

You have a right to follow your own beliefs and have your own ideas.



ARTICLE 10

The right to say what you think

You have the right to speak out, even if other people disagree with you.



ARTICLE 11

The right to freedom of association

Services should not stop you from going out and meeting other people.



ARTICLE 14

The right not to be discriminated against

You have the right not to be treated badly because of being a woman or a man, black or white, having a disability or for any other reason.

Your services

Service users are not always told who provides and pays for their service. It is important to know who controls your service if you want to make changes.

It is also helpful if you can find a worker who is on your side and will help you make changes happen. Ask your social worker or support worker to help you find out who provides and pays for your services.



Getting what you need

If you need support to live your life independently you can talk to your local social services department (Adult Care). You can ask for a Community Care Assessment.



A Social Worker will come to see you. The Social Worker will ask you questions to find out what support you need. They might provide:

- Support at home
- Help with changes or adaptations to where you live
- Support to do things during the day, like go to college
- Meals.

If you think you need help during your assessment, or you disagree with an assessment, then contact your local service user organisation or advocacy organisation. They should have experience of supporting people through assessments and what to do if you disagree with an assessment.



If you and your social worker agree with the amount of support you need, then you should think about how you want to receive that support. Do you want to manage the money yourself (with help if you need it) so you can organise your own support? Do you want to get support from a provider that you already know about?



You don't have to say yes to the service your social worker offers. Get help from your local service user organisation or brokerage organisation if you want something different.

If you already get a service but you don't agree with the amount of service you get or you don't like the service, then contact your social worker or get help from an independent organisation.



Taking part

Some people want to get involved in how their service is run and organised.

Service providers should have ways for users to get involved in this way if they want to. Having service users involved in a service is a good way to change things when a service needs to be made better.

Some service users enjoy getting involved like this and can get a lot from the experience. You can feel like you are doing something useful and helping to improve services and make things better for other people.

There are lots of ways to get involved.

For example:

- Help to interview and choose support staff
- Join a service consultation group
- Join a tenants or residents group
- Go to meetings, workshops and conferences with service bosses
- Help train staff and service people
- Campaign for changes with an independent
- Advocacy or service user organisation
- Join a local Partnership Board.



A lot of service users start to get involved when they have a problem that they need to sort out. When they do this they find that there are other ways to get involved as well. Getting involved can be a good way to learn new things, make friends, and talk about things with other people.



If you are not sure whether to get involved, why not give it a try? Once you get started, you should get the chance to suggest new ideas and try different ways of doing things.

Sometimes you can get paid for taking part – though this can be difficult if you get benefits. There are strict rules about getting paid while you are receiving benefits.



The person who helps you with your services should know about what their service does to involve service users. If they don't know, ask them to find out.

In some places there are independent organisations that deal with user involvement – some will be run by service users. Contact the SOLNET website to find your local user controlled organisation at:

www.solnetwork.org.uk



Shaping Our Lives will publish a resource pack for service users and service providers on all aspects of user involvement. Contact them on:

Tel: 0845 241 0383



You can also find out about local groups by contacting your local council for voluntary service. The National Association for Voluntary and Community Action (NAVCA) will be able to give you a contact in your area (address at the end of this report).

Your support money

Direct payments

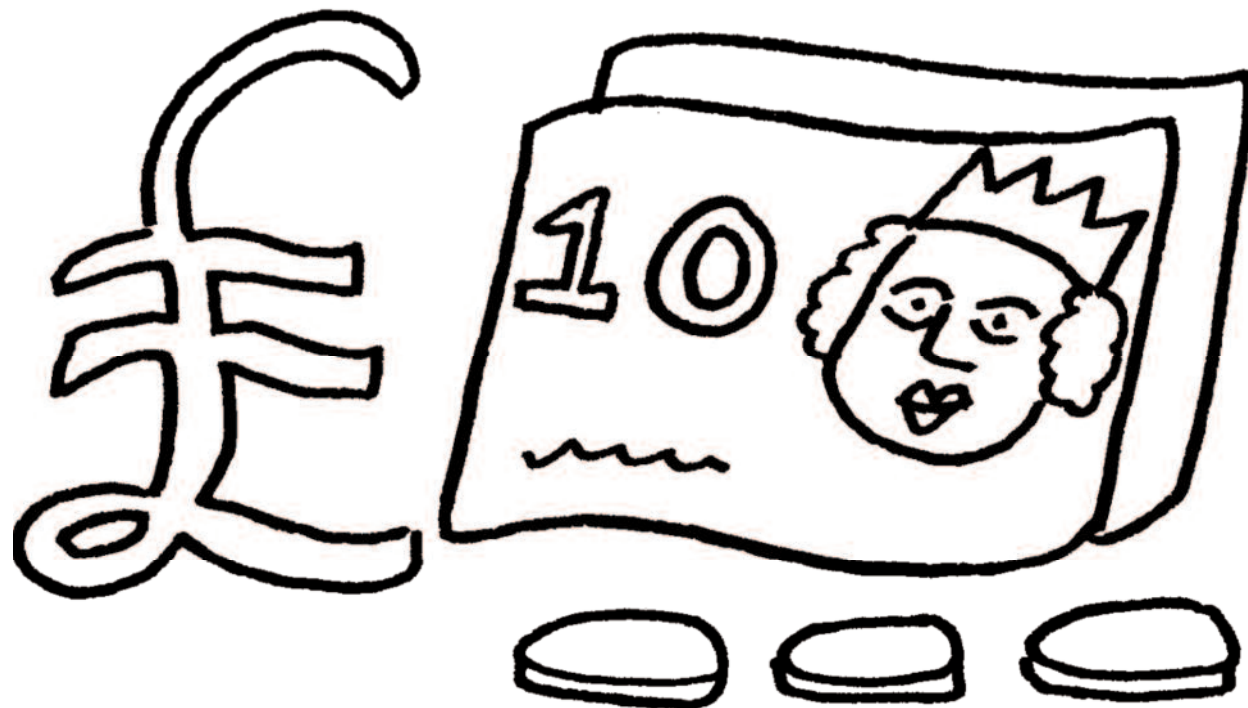
One way to get more control over the money spent on your support is to get a direct payment.

With direct payments, Adult Services give you all or part of the money for your service. You choose the best way to spend the money to meet your needs.

Lots of people use their direct payment to employ their own support workers. This gives people a person centred service because they are in control of it. This might sound difficult but you can get help to set up a direct payment and to manage the money. You don't have to do it all yourself.

The best place to get help is from your local independent direct payments support organisation or local disabled people's organisation.

To find out more about direct payments contact the National Centre for Independent Living at: www.ncil.org.uk



Personal budgets

Personal budgets are another way of getting control over the money for your support. Personal budgets are new but they are spreading across the country. Personal budgets start with your personal support plan, which you decide on (with help if you need). This looks at your whole life and what support you need to live it.



The personal budget for your support is used to pay for the support, equipment or activities you need to live your life. You can get help from a social worker or an advocate or broker who can help you decide how to spend the money. They can help set up your support in the way you want.

You can have the money as a direct payment, so it comes to you, or you can ask your Adult Services department to arrange things for you.

To find more contact your local Adult Services or service user organisation see the SOLNET website at: www.solnetwork.org.uk

Benefits

You are probably entitled to a number of state benefits. How much you get will depend on things like your housing, whether you have savings, whether you live on your own and whether you have children.

There are benefits to help with things like daily living, housing costs, council tax and childcare. If you are not sure what benefits you get or could get, ask someone to help you find out.

You should control how your benefits are spent, with support if necessary, unless you have someone who has been given a legal responsibility to manage your money for you.

Benefits can be complicated. To find out more and get advice, you need to contact a specialist advisor, such as:

Disability Alliance Helpline

Tel: 020 7247 8776 (textphone available)
www.disabilityalliance.org

Benefits Enquiry Line (for disabled people)

Tel: 0800 88 22 00

Citizen Advice Bureau

contact www.nacab.org.uk to find out local details



Your housing

People live in all sorts of ways and all sorts of housing.

Most people live in one of the following:

- A home that they own and pay for
- A home that they rent from a local authority, housing association or other landlord
- A residential home
- Someone else's home (usually a family member or friend).

People can live alone, with the families they grew up with or the friends and families they make as adults.

Some disabled people are not happy about where they live. They are not given a choice about where they live or who they live with.

Advice

You can get information and advice if you are not happy about where you live, or you need more information about your choices.

For housing advice, contact **Housing Options** or **Shelter** or the **Citizens Advice Bureau** (addresses at the end of this report).

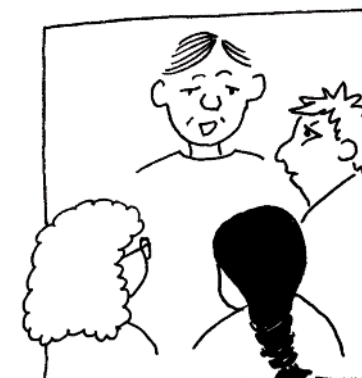
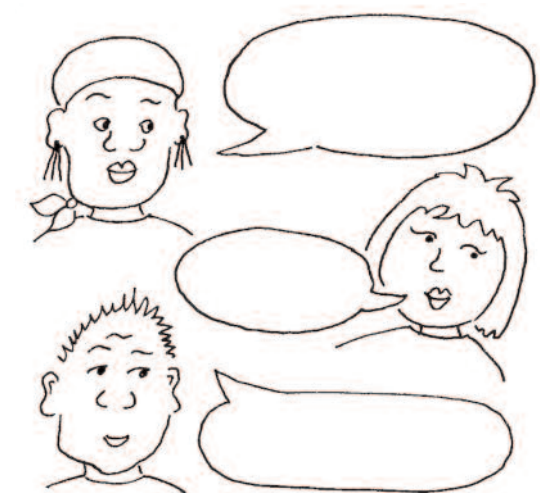
What next?



Person-centred support means support that helps you live life in the way you want to. It means including you in everything, helping you live an independent life and making sure you get your human rights.

Service users in this project said they really want person-centred support. They want support that is:

- Respectful
- Kind
- Polite
- Good at listening
- Honest
- Reliable
- Flexible
- Practical



The Standards We Expect Project found out that things can change but only when all service users are involved in services and their voices are listened to and acted on.

This takes money, time, skill, good staff, the right values and social care that really listens to service users.

Then person-centred support can happen for everyone.

Useful organisations

Benefits

**Benefits Enquiry Line
(for disabled people)**
Telephone: 0800 88 22 00

Equality and human rights commissions

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

Equality and Human Rights Commission (Wales)
Freepost RRLR-UEYB-UYZL
1st Floor, 3 Callaghan Square
Cardiff CF10 5BT
Telephone: 0845 604 8810
Textphone: 0845 604 8820

Equality and Human Rights Commission (Scotland)
Freepost RRLG-GYLB-UJTA
The Optima Building
58 Robertson Street
Glasgow G2 8DU
Telephone: 0845 604 5510
Textphone: 0845 604 5520

National service user and disabled people's organisations

National Centre for Independent Living
Unit 3.40, Canterbury Court
1-3 Brixton Road
London SW9 6DE
Telephone: 020 7587 1663
Advice Line: 0845 026 4748
www.ncil.org.uk

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

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

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

SOLNET website of organisations of people
www.solnetwork.org.uk

Other national organisations

Action for Advocacy
PO Box 31856
Lorrimore Square
London SE17 3XR
Telephone: 020 7820 7868
www.actionforadvocacy.org.uk

Disability Alliance helpline
Tel: 020 7247 8776 (textphone available)
www.disabilityalliance.org

Housing Options
Stanelaw House
Sutton Lane
Witney
Oxfordshire OX29 5RY
Telephone: (0845) 456 1497
www.housingoptions.org.uk

National Association for Voluntary and Community Action
The Tower
2 Furnival Square
Sheffield S1 4QL
Telephone: 0114 278 6636
Fax: 0114 278 7004
Textphone: 0114 278 7025
www.navca.org.uk

National Association of Citizen Advice Bureaux
www.nacab.org.uk
www.adviceguide.org.uk

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

Shelter National Helpline
Telephone: 0808 800 4444
www.shelter.org.uk

Values Into Action
PO Box 59043
London E13 3AZ
Telephone: 07754 157718
www.viauk.org

More about the Project

The Standards We Expect project was a research and development project paid for by the Joseph Rowntree Foundation. It started in 2005 and ended in June 2009.

This project was about person centred support. This means services that put the person at the centre. The Project wanted to find out how to make person centred services happen better and faster across the country.

The Project worked in eight areas across the United Kingdom. The work in each area was different, depending on what was happening in each area and what people wanted to do.

In each area, the Project asked:

- What does person centred support mean for people?
- What stops it from happening?
- What helps it to happen?

The Project worked with service users, carers, staff and organisations. But the Project worked most closely with service users and staff because what they say is often not listened to.

The Project ran national 'Get Togethers' and training workshops for everyone.

The Project was run by a group of four organisations and four individuals, led by Shaping Our Lives, the national service user network. The other partners were Values Into Action, the Centre for Social Action at De Montfort University and the Centre for Citizen Participation at Brunel University.

We also worked with a network of twelve more organisations which were part of the Project to support change more widely.



Reports from the Project

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

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

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

Supporting People: towards a person-centred approach

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

Published by Policy Press 2011

Supporting People: towards a person-centred approach Findings

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

Published by Joseph Rowntree Foundation 2011

Supporting People: the big issues

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

Published by Joseph Rowntree Foundation 2011

Supporting People:

a summary in easy words and pictures

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

Person-Centred Support: a guide for service users

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

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

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

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

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

Person-Centred Support: choices for end of life care

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

Working towards Person-Centred Support: a local case study

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

THE STANDARDS WE EXPECT...

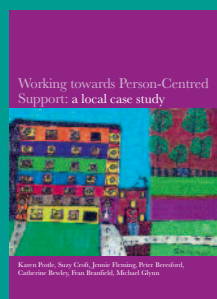




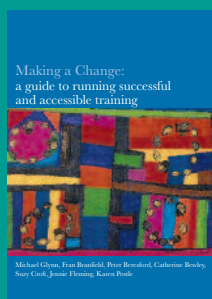
Front cover illustration 'Cycling the hills to camp in the countryside' © Kevin Chettle and with permission from Advocacy in Action

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

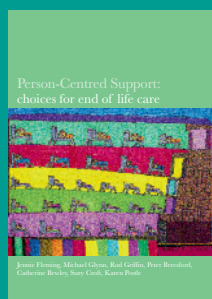
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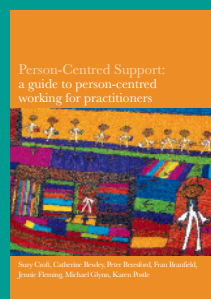
Working towards
Person-Centred Support:
a local case study



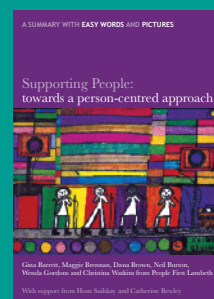
Making a Change:
a guide to running
successful and
accessible training



Person-Centred Support:
choices for end of life care



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



Supporting People:
towards a person-
centred approach