A SUMMARY WITH EASY WORDS AND PICTURES

Supporting People: towards a person-centred approach



Gina Barrett, Maggie Brennan, Dana Brown, Neil Burton, Wenda Gordons and Christina Watkins from People First Lambeth

With support from Hom Saihkay and Catherine Bewley

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By Gina Barrett, Maggie Brennan, Dana Brown, Neil Burton, Wenda Gordons and Christina Watkins from People First Lambeth

with support from Hom Saihkay, People First Lambeth and Catherine Bewley, the Standards We Expect Project

We would like to thank all the service users, staff, managers, trainers, co-workers and friends who took part in this work. Without you this Project would not have happened. We hope this summary is useful for you.

Most of all, a massive thank you to the fantastic Steering Group at People First Lambeth, especially Gina, Maggie, Dana, Neil, Wenda and Christina, with great help from Hom. You are brilliant!



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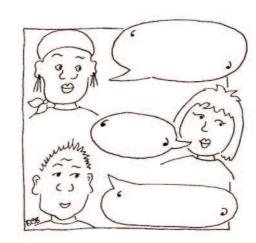
What is in this summary?

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About this summary

The summary is very good. It is easy to read and it's also a good topic. It will help people with leaning difficulties to understand more about person-centred support.



I think person-centred support is good for people when it works but for some it has not worked due to a lack of staff training and money. It's really important for people in services to make changes but not then put the changes back in a drawer.

Services need to listen to what people think is important. People want to take more control of their support and their lives. Services should try to change, so that people's goals and dreams can be a reality. This summary will help staff be more person-centred and use their time more wisely.

I think now people are taking charge of their services and having a say. People want services where they are at the centre. People who use services need to think about what good support means for them and how they want to be supported. I think this summary will help them do that.

Mark Brookes

Service Audit Worker, Dimensions UK Member of People First Havering Consultant for Values Into Action

About the book 'Supporting People' that this summary is about

Every so often, there are important books. Social Care has had some of those. Just occasionally there are books that change the way we view what we do and that redefine our work.

This book deserves to be one of the rare game changers. At the heart of personalised care lies a move to giving people genuine control over the way that they are supported. In part that's the transfer of the main resource, money, through personal budgets and direct payments. It should also be about giving people a real say in the design of care and support services, so that outcomes and resources are shaped around you personally.

This is the first book to examine over time the principles of producing care and support together in ways where people receiving support are equal partners. Within that spirit the book also offers the reflections of staff, service users and others on the barriers and blocks in the way of change and improvement.

Social care is reforming and is becoming more personal. It has some way to go to secure and sustain that vision in ways that work consistently for all who need support. The content and messages in this book deserve serious consideration by all who shape the care system for themselves or others. If we address the challenges voiced clearly by people receiving care and support contained in these pages then we will succeed in this task.

Peter Hay

President, Association of Directors of Adult Social Services Strategic Director for Adults and Communities, Birmingham

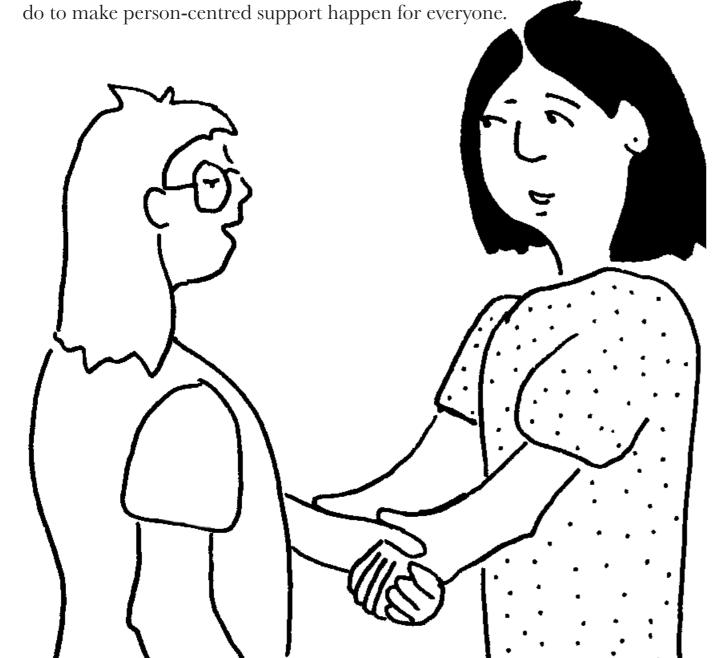
Introduction

This summary is about people getting the support they need in the way they want it. We call this **person-centred support**.

This summary will tell you lots of things about a project called **The Standards We Expect**. This summary is about a very big book written by the Project.

This summary will tell you what service users and staff have said about person-centred support.

This summary will tell you what these people think we have to



Who wrote this summary

The Standards We Expect Project asked People First Lambeth to write this summary with easy words and pictures.

People First Lambeth is an organisation run by and for people with learning difficulties in South London.

The **Steering Group** at People First Lambeth wrote this Summary. These people were in the Steering Group:

Gina Barrett

Gina has been a member of People First Lambeth for over eight years. She is a member of many groups and a management committee member. Gina was co-chair of the Partnership Board and runs training with professionals and other groups.

Maggie Brennan

Maggie has been a member of People First Lambeth for 25 years. She has travelled nationally and internationally on behalf of People First Lambeth and National People First. Maggie worked for People First Lambeth for eight years and was a Management Commitment member. She has run many groups, been involved in lots of projects and co-wrote the book 'We Are Not Stupid'.

Dana Brown

Dana has been a member of People First Lambeth for over ten years. She was a member of the Management Committee and the Friendly Group at People First Lambeth. Dana has also been a trustee of Lambeth Mencap. She has helped run many events and conferences, including an event about jobs for Mencap Pathway and events for Lambeth Partnership Board.

Neil Burton

Neil has been a member of People First Lambeth for over ten years. He has been co-chair of the Partnership Board and is a Management Committee member. Neil has set up and led many conferences and meetings.

Wenda Gordons

Wenda has been a member of People First Lambeth for over 20 years. She has travelled nationally and internationally for People First Lambeth and National People First. Wenda was co-chair of the Partnership Board for three years and has been a member of the Management Committee and Friendly Group at People First Lambeth. Wenda runs training with professionals and other organisations.

Christina Watkins

Christina has been a member of People First Lambeth for three years. In that time she has run a story-telling group and a walking group. She has been involved in many projects, training and conferences. Christina is involved in the London Network on Parenting.

The Steering Group was supported by **Hom Saihkay** from People First Lambeth. Hom worked for People First Lambeth from 2004 to 2011. She supported the Moving On project and many other research groups. She worked on the quarterly People First Lambeth newsletter, led work on the website, and supported many accessible publications at People First Lambeth.

The Steering Group was also supported by **Catherine Bewley** from the Standards We Expect Project.

How we wrote this summary

Catherine prepared a first draft of the words from the big book. The Steering Group then worked on the words and the pictures to make them accessible for everyone.



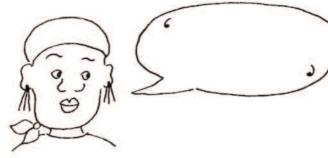
The Steering Group also worked out the most important things that should be in this summary. The Group talked about the ideas in the big book and worked out how it could all make sense.



The Steering Group said this work was a challenge. Some of the ideas and words were very difficult at first. The group had to work hard.

What people said

In this summary we sometimes use the real words people said in the Project.



You know we are using people's real words when you see words inside a speech bubble.

We tell you who said the words but we don't give names because the Project agreed to keep that a secret. We write 'service user', 'staff' or 'manager' so you know which group the speaker belongs to.

We hope you find this summary interesting and useful!

The Steering Group at People First Lambeth



About the Project

All the ideas in this summary come from a national project called The Standards We Expect.

THE STANDARDS WE EXPECT.



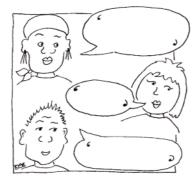






The project lasted four years. It asked what service users want from their support.

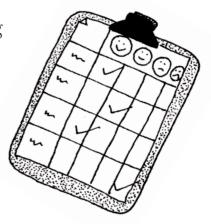




The Project worked hard to get the views and experiences of service users, as well as staff who work with people day-by-day.

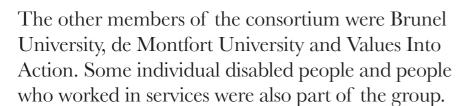
The project tried to find out what stops people having the support they want and what we can do about this.

This summary is about what the Project found out.



Who ran the Project?

A group called a consortium ran the Project. The group was led by a national organisation run by service users called Shaping Our Lives.







Who was involved in the Project?

The project included all service users over 18 years old.

It worked in eight parts of the country. Another 12 areas also got involved.

The project worked with over 250 people.

The service users involved were:

- Young disabled people living in a home
- Disabled people living in the countryside who used a community centre
- Homeless people
- People with mental health problems
- People with drink or drug problems
- Single parent families
- People with learning difficulties from an Asian community
- People with learning difficulties who live in the countryside
- People with learning difficulties who live in residential homes
- Older people near the end of their lives
- Older people with dementia.

Over 100 people took part in training.

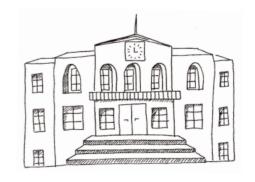
Over 100 people came to conferences called 'get-togethers'.

You can find a full list of the reports written by the Project at the end of this summary.



What is social care?

Social care means all the services that organisations give people who need some help or support to live their daily lives.





Social care is big business. Local councils spend £14.2 billion pounds on social care for adults every year.



About 1½ million people work in social care.



Who needs social care?

Lots of people need support to live.

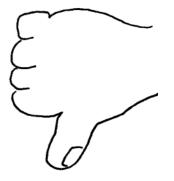
People can need support at any time in their lives.

About six million people get social care support.

The problem with social care

People in this Project said:

- Sometimes social care isn't very helpful.
- Sometimes social care doesn't keep its promises.
- Social care can take a long time to change.
- Social care can stop people being independent and in control of their own lives.
- Some people feel very left out of changes that are good, like direct payments.



Paying for social care

Social care is not funded straight out of taxes like health services.



Most people have to pay for part of their social care.

Lots of people think that there isn't enough money to pay for all the support that every one needs.

Not enough money for services means only some people can get support.

A lot of people rely on family and friends to help them out.



Not enough money means people can't always get support for the things that make life important.

Now you get support going shopping. If you are lucky you will get support going to the doctor's and that's about it. We used to get support to go bowling, to go to the pictures and to go to play pool. You can't do that any more. **Service user**



People feel sad and fed-up about services when there isn't enough money.

People feel angry and powerless.

All it is, is cut-backs, cut-backs or no money available ... There is a lack of funds here to pay for these things and that is that. **Service User**

Person-centred support

Person-centred support means support that helps you live life in the way you want it.

It means including you in everything.

It means helping you to live an independent life.

It means making sure you get your human rights.

Person-centred support is about people being flexible and working together.

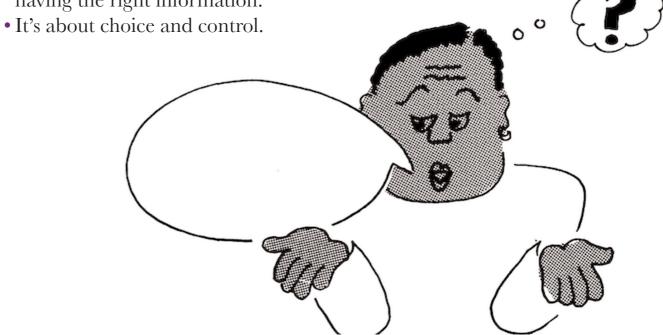




It's not another job, it's **the** job. **Staff**

What does person centred support mean?

- People said it's not like a box of tools.
- It's really about relationships.
- It's about values, listening, being positive, being accessible, having the right information.



This project came up with some important things about what good person-centred support is like:

- 1. People are at the centre of things.
- 2. People are treated as individuals.
- 3. People have choice and control over their lives.
- 4. People get help to set goals for their lives.
- 5. There is a good relationship between service users and staff. This includes trust, confidence and getting things done.
- 6. Staff listen to people.
- 7. Staff give people the right information in the way they want it.
- 8. Support is flexible.
- 9. Support is positive.
- 10. Staff use the right words in a way people can understand.

Service users said these things about their support:

I may need physical care but I don't need people to think for me. **Service user**

Your worker can't tell you what you need, you know what you need. **Service user**

What I want is to be listened to and respected. **Service user** You need the right information to help you choose. **Service user**

Personalisation

Personalisation is a long word! It is used by government and councils.

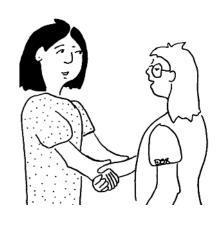
It means how services are run to help people have more choice and control.

Service users and their organisations sometimes feel left out of these developments.

Independent living

Disabled people started the idea of independent living. Independent living means:

- Everyone is important.
- Everyone can share their choices with other people who listen well.
- People have a right to control their own lives.
- People have a right to be full citizens.
- Independent living is based in the social model of disability and civil rights.
- It doesn't mean doing everything for yourself. It means having support in the way you want it to live equally like everyone else.
- Independent living uses the word 'support' instead of 'care'.





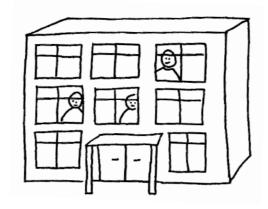
Things that stop person-centred support

In this project we found that these things stop personcentred support from happening:

- Not enough money.
- Not enough good workers that get paid well and can stick around.
- Too much support that relies on families and friends.
- Services run with rules, like Institutions. (More about institutions in the next section).
- Too much paperwork and red tape.
- Too much worry about risk.
- No flexibility.
- Services that tell you how to live and what to do.
- Support that doesn't reach everyone.
- Not having equal rights to things that everyone else does.



Social care organisations



Institutions

Organisations often end up with rules about how to run things. The bigger they are, the more rules there are.

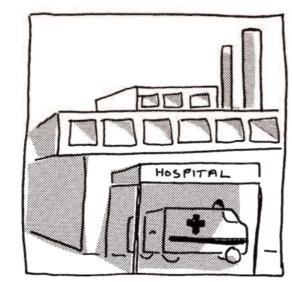
Service users often feel like they have to fit around the rules, not the other way around.

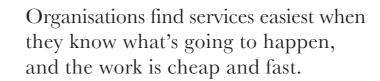
Some problems with social care organisations are:

- They give people labels which are very hard to change.
- Everyone with the same label gets lumped together.
- People have to live in groups, whether they want to or not.
- There are rules about things like eating and sleeping but the service ignores things like people's feelings and hopes.
- People have to follow the rules and routines.
- Service users find it hard to mix with other people who are not in services.

This is called being 'institutional'.

These things happened in long-stay hospitals in the past. But it still happens today in residential homes and even in people's own homes.





This can means services are all the same. Rules and targets become too important.



We are not allowed to talk to people on the other table. We wait for staff to finish their tea. When staff get up, they say what people are on the rota to do. You can't get up until the staff say so. **Service user**

I would really like to send the message that not everything can be measured, because what is a huge achievement for someone might not be for another ... How do you measure that? You can't measure pain. You can't measure pleasure. It is all an individual thing, isn't it? So why put in tick boxes and why pay lip-service to something? **Staff**

Taking risks

Person-centred support is about choice and control. But organisations have rules about health and safety. These things can be a conflict.



Me and my mate were supposed to go to see the motor racing last summer. We booked tickets and got all excited. But then we couldn't go, on the very last day, because of access and I was not happy and nor was my mate ... We had to check the ground to see if it was level and it wasn't. They rang up and they had to cancel it. **Service user**

We're not allowed to go in our fridge in our own home to get the milk out because our manager says it's all to do with health and safety. I'm sure no one says that to you in your home, so why is it different here? **Service user**

Risk is part of life.

But staff can feel worried that they will be blamed if there is an accident.

Some people, they undoubtedly want to take that risk. They know what they are doing. They want to be free to do as they like. But you're saying, 'No I can't do that. I'm going to get in trouble if you do that, because I haven't protected you enough'. **Staff**

Self confidence

You need a bit of self-confidence to make choices. Living in social care can take your self-confidence away.

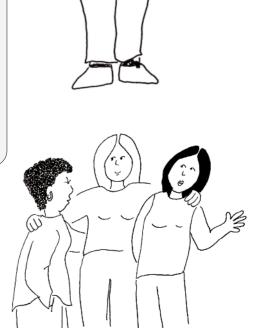
Thirty years is a long time in a residential home. I'm very happy now. I've got my own flat ... At the beginning, it was a bit daunting. I remember the day I moved in. I was all alone. I'm more in charge now. It is my life.

Service user

People don't like institutions but they are also worried about being lonely.

Service users like services that help them meet others, learn together and have fun.

I go to a centre and a lot of the things that I am accessing now, I only found out about from people that actually attended the centre. **Service user**



Staff

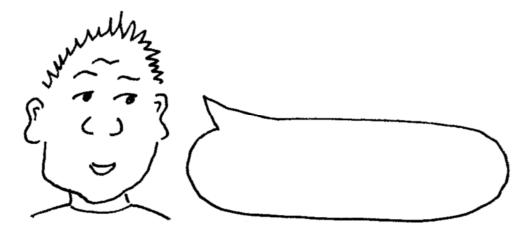
Service users said that how staff work with you is the most important thing about support.

Staff should focus on people's rights and what they want to do with their lives.

Person-centred support is about supporting people to achieve what they want from their lives.



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



Sometimes they respect you, sometimes they don't. Service user

What service users said about staff

It can be hard to get support for what **you** want to do, not what **they** want you to do. **Service user**

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'. **Service user**

You sort of say to them 'Oh I want a shower and a wet room', and they write it all down and then come and put a bath in and you get a bath seat and you go, 'Yeah, thanks, but a bath's totally useless'. **Service user**



What staff said

The staff involved in this project said these things were important for them:

- Training
- Supervision and support
- The chance to work flexibly
- Building a relationship with service users
- Being valued.

Unless it's relationship-centred the person-centred bit doesn't work ... When you pull right back to the bones of it, it is often the relationship the staff have with an individual that makes a difference, that is the good quality stuff and that is really difficult to pin down. Manager

This project found that staff who are valued say:

- They get regular good supervision.
- They have regular team meetings. NO CJHANGE
- They can talk about their views and ideas.
- Things change.
- They can make decisions.
- There is good communication with managers.

If I'm stressed out, I would like to be able to just come into a room and talk to my supervisor or manager about it ... rather than keeping something bottled up, I'd like to vent it out. **Staff**

Social care work can be stressful. Staff need good supervision and support.



What is a carer?

Carers are family and friends who end up giving support to people in a similar way to staff but without being paid.



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There are about six million unpaid carers in the UK.

Social care makes carers into a part of the system. This saves money but doesn't always help service users get good person-centred support.

The problem for service users

This project heard about love, loyalty and commitment by carers.

But being a carer changes the relationships between people in families.

Your parents are a massive thing, but they need to know that, yeah, they can care for you, and yeah, they can do what they like for you, but they need to know that you want your space. **Service user**

Sometimes carers can stop people getting person-centred support.

It took a long time. I had to wait until after they [my parents] died to get married. **Service user**

It can be very difficult to stand up to your family and make your own decisions.

The project found that advocacy is very important when service users clash with family and friends.

For older people in care, it is sometimes their sons and daughters that get involved in decisions.



Unfortunately what sometimes happens is their families take over and they put their wishes first. I think that is still an old fashioned thing in nursing homes, where the resident wasn't asked, but the families were asked. I think that is changing, but I think it is taking some time. **Manager**

The problem for families

For family and friends, they often feel like they are expected to care.

Most carers don't have the right information, advice, support and advocacy to put their relative's rights first.

Some family members are very worried about the future. They worry about support for their relative after they die or get ill. They worry about taking risks.

Families can also be great supporters. They can speak out for their relative's independence.

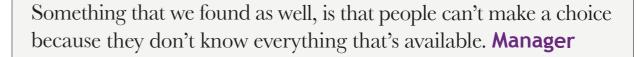




Information and access

Information

People need to know about their options.



But leaflets are not the only answer. Service users said information needs to be accessible but it also needs to be useful and to make sense.



25



Service users say what they need most is a person to help them work out what support they need and then get it.

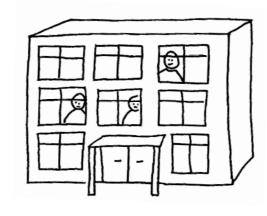
Some people go to user-controlled organisations or brokers for advice and help. A lot of people said they find it easier to talk to other service users.

[The centre] is a goldmine of information. Ninety percent of what I know now, I found out from other people. It's not written down anywhere. **Service user**

Access

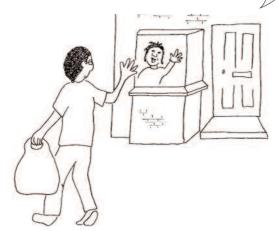
The project found that people were kept in homes and institutions because there wasn't enough accessible housing.

But it's not just about where you live. People have the right to take part in everything in their local community.



I mean it's no good just making the house adapted for someone to live in if they can't get into their neighbour's house, or get into the local shops, or get in the local pub and then they become isolated in that building that is adapted for their needs. **Staff**

Not being able to get out and about stops people from taking part equally in society.



Transport is a big problem for many service users. Things are very difficult for people in countryside areas. It can be hard to get staff and to move around.

If you live in the city you have more opportunities. If you live out in the country, you have to worry about how to get anywhere. **Service user**

Problems for Black and Asian people and people from Minority Ethnic Communities

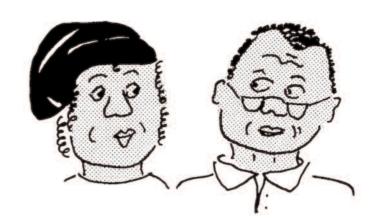
The project found that Black, Asian and Minority Ethnic families may not know about services and how the social care system works.



Sometimes people don't trust services.

In terms of families we work with, they have fears of the system, especially coming from different cultural communities. **Manager**

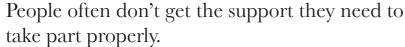
In one area involved in the Project, staff worked in a slow and careful way to build trust with the local community. This was really important to help service users from Black, Asian and Minority Ethnic Communities to get the support they need in the way they want.



Our worker is spreading information to the community about services. She works with professionals to raise cultural awareness. Progress is steady but slow. It is a learning curve. **Staff**

Getting involved

Lots of people feel left out of making decisions about services. Getting involved can be very hard.



I'd like to change the meetings. Sometimes I get bored. It's difficult to understand what people are saying. Service User

Lots of people don't like meetings.

There often isn't enough time to get involved properly.

Other people worry that they will get picked on if they complain about the service.

A lot of people said they never knew what happened after the consultation.

Disabled people need feedback. What happens to our ideas? **Service User**

The project found out that good involvement happens when:

- People are involved as an everyday, on-going thing.
- Organisations really listen.
- Organisations make decisions based on what service users say.
- People are involved right at the start of an idea.
- Lots of different people are involved in lots of different ways.
- People have the right access, information, support and style to help them take part.
- Service users can meet together to share experiences.
- Service users are involved in choosing and training staff.
- Service users are involved in making decisions about services.

Staff also need a chance to be listened to and get involved.



The whole summary is about making things change.

Lots of people in the Project were doing what they could to make things change for the better.

But there needs to be support from government and society to really make change happen and there needs to be enough money.



How organisations, services and staff do their work is really important.

What we learned about change

We did a lot of involvement and development in this Project. We learned that:

- Lots of people do want to be involved in change.
- People can work together to make change happen.
- People need time to meet and make change happen.
- Service users and their organisations must be involved.

What makes change happen?

We learned that social care can change and can get better if:

- People who use services are involved.
- Staff are given the support and training to do their jobs in a person-centred way.
- Staff get better status and pay.
- Support is more personal, controlled by service users.
- There is a positive way of dealing with risk.
- People being equal is seen as important.
- There is enough money.
- Social care is for everyone, based on rights.
- The values of rights and independent living are at the heart of services.
- Services are about the whole person, not a narrow idea of 'needs'.
- Social care organisations have less rules and red tape.



The main things

This summary is about people getting the support they need in the way they want it. We call this **person-centred support**.

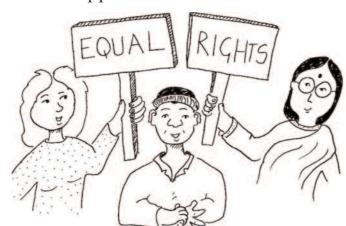


Person-centred support means support that helps you live life in the way you want to. It means including you in everything, helping you live an independent life and making sure you get your human rights.

Service users really want person-centred support.

They want support that is:

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



Lots of staff want to work like this but find it hard when social care organisations work like institutions. There can be too many rules, too much paperwork and a lot of fear about risk.

When this happens, service users don't get their human rights. They don't get a chance to live in the same way as everybody else.

Something has to change!

The Standards We Expect Project found 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.

Where to get help



If you want to know more about human rights, contact this organisation:

Equality and Human Rights Commission (England)

Freepost RRLL-GHUX-CTRX Arndale House Arndale Centre Manchester M4 3EQ Telephone: 0845 604 6610 Textphone: 0845 604 6620 Fax: 0845 604 6630

Equality and Human Rights Commission (Wales)

www.equalityhumanrights.com

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 RRLL-GYLB-UJTA
The Optima Building
58 Robertson Street
Glasgow G2 8DU
Telephone: 0845 604 5510

Testphone: 0845 604 5520

If you want to get in touch with service users around the country and be part of a movement, contact this organisation:

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

If you want to know more about independent living, direct payments or personal budgets, contact this organisation:

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

If you want to contact your local self-advocacy organisation, try here:

Self advocacy

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

People First

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

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Reports from the Project

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

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

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

Supporting People: towards a person-centred approach

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

Published by Policy Press 2011

Supporting People: towards a person-centred approach **Findings**

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

Published by Joseph Rowntree Foundation 2011

Supporting People: the big issues

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

Published by Joseph Rowntree Foundation 2011

Supporting People:

a summary in easy words and pictures

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

Person-Centred Support: a guide for service users

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

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

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

Making a Change:

a guide to running successful and accessible workshops and training

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

Person-Centred Support: choices for end of life care

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

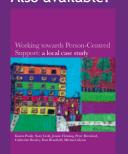
Working towards Person-Centred Support: a local case study

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

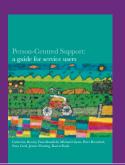


This report is one of a series linked with the national Standards We Expect Project supported by the Joseph Rowntree Foundation. The purpose of this national project was to develop person-centred support in social care and other services, in line with the 'standards' that service users wanted. It focused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

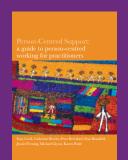
Also available:



Working towards Person-Centred Support: a local case study



Person-Centred Support: a guide for service users



Person-Centred Support: a guide to person-centred choices for end of life care working for practitioners



Person-Centred Support:



Making a Change: a guide to running successful and

accessible training



