

# THE STANDARDS WE EXPECT...



dmu.ac.uk  
**DE MONTFORT  
UNIVERSITY**  
LEICESTER

**Shaping  
Our Lives**  
National User Network



**CENTRE FOR  
citizen  
participation**  
Brunel University



The UK-wide campaign  
with people who have  
learning difficulties

**Values Into Action**

## Person Centred Support A Guide for Service Users



Useful information for service users who got  
involved in The Standards We Expect project  
about person centred support

March 2008

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

This information pack is for the service users who came to our training workshops and took part in our project. We want to share some useful information and good ideas to help you get the services and lives *you* want.



**The Standards We Expect project ends on 30 June 2008. Up to then you can contact:**

Michael Glynn

The Standards We Expect Project

Centre for Social Action

De Montfort University

The Gateway

Leicester LE1 9BH

Telephone: 0116 257 7773

Website: [www.thestandardsweexpect.org.uk](http://www.thestandardsweexpect.org.uk)

Email: [standardsweexpect@googlemail.com](mailto:standardsweexpect@googlemail.com)



**From July 2008, if you need to talk to someone, contact:**

Shaping Our Lives

National User Network

BM Box 4845

London WC1N 3XX

Tel: 0845 241 0383

[www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)



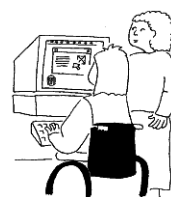
# What Is In This Pack?

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This pack is for a wide range of service users who took part in The Standards We Expect project. We have tried to make the pack useful and easy for everyone.

There are contact details for lots of other organisations and helplines in this pack. You can find them next to these pictures:



Pictures are from the  
Change PictureBank



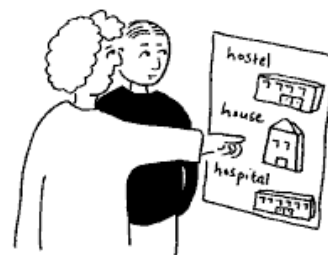
# 1. What Is Person Centred Support?

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 8 important things about person centred support. They are:

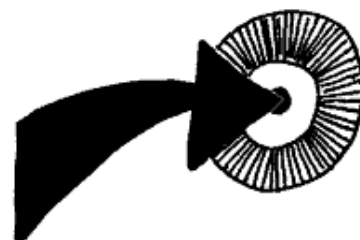
## 1. Choice and Control

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, the 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 to make person centred support happen.



## 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.





## 2. What is 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, or the barriers approach to disability.

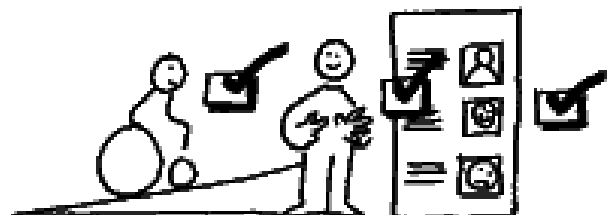


This idea looks at the way people and society make disabled people's lives difficult. These are barriers like poor access to buildings, treating people unfairly at school, college or work, and not having the right services and support.

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



It is also called the 'equalities' approach because it's about having the same life chances and opportunities as everyone else. It's about what society, organisations and people need to do to make equal chances happen.



This project looked at services from this barriers and equalities approach.

The project thinks that person centred services are about helping people to live their lives as they want to. To do this they need to have choice and control over the support that they get.







### 3. 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.

You can look at the SOLNET website run by Shaping Our Lives. This website lists over 200 organisations of people who use services. It also has information about events and opportunities to get involved:  
**[www.solnetwork.org.uk](http://www.solnetwork.org.uk)**



You can also contact:  
**Shaping Our Lives**  
**National User Network**  
**BM Box 4845**  
**London WC1N 3XX**  
**Telephone: 0845 241 0383**



**Website: [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)**





## 4. Your Rights

### Your Right to Make Decisions

There is a new law called the Mental Capacity Act. This new law is all about 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 new 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
  - you are disabled
  - you can't make big decisions
  - or if you couldn't make a decision in the past.



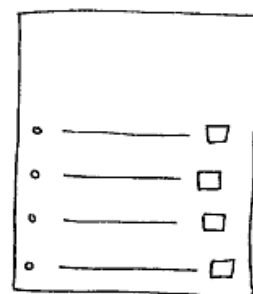
## Your Right to Equality

There is a law called the Disability Discrimination Act. It says you should not be treated unfairly because you are disabled.



This law is about things like:

- shops and services
- health and social care
- school and college
- getting a job
- renting or buying a house.



Employers and organisations that provide any type of goods or services are breaking the law if they treat a 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.



Public organisations - like councils, colleges, and public transport services - must have a policy that says what they will do to make disabled people more equal in their services.

If you have been treated unfairly you can:

- tell the people running the service how they could make things better
- tell the people running the service that the Equality and Human Rights Commission can help
- ask the Equality and Human Rights Commission for help.



For general help and information contact:

**Equality and Human Rights Commission Helpline**  
**Freepost RRLG-GHUX-CTR**  
**Arndale House, Arndale Centre**  
**Manchester. M4 3EQ**

**Telephone: 0845 604 6610**  
**Textphone: 0845 604 6620**  
**Fax: 0845 604 6630**  
**[www.equalityhumanrights.com](http://www.equalityhumanrights.com)**



In Wales contact:

**Equality and Human Rights Commission Helpline**  
**Wales**

**Freepost RRLR-UEYB-UYZL**  
**1st Floor**  
**3 Callaghan Square**  
**Cardiff**  
**CF10 5BT**

**Telephone: 0845 604 8810**  
**Textphone: 0845 604 8820**



In Scotland contact:

**Equality and Human Rights Commission Helpline  
Scotland**

**Freepost RRLL-GYLB-UJTA**

**The Optima Building**

**58 Robertson Street**

**Glasgow**

**G2 8DU**

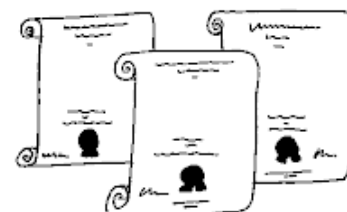
**Telephone: 0845 604 5510**

**Textphone: 0845 604 5520**



## **Your Human Rights**

There is a law called the Human Rights Act. This law gives everyone in the country rights as human beings. It puts these rights under headings called 'Articles'.



### **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 respect for 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.

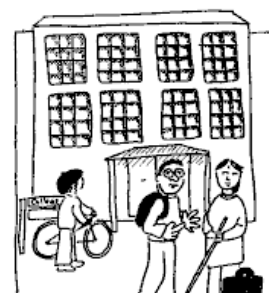


## **Article 14 -The right not to be discriminated against**

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.



The Human Rights Act also says you have the right to keep and enjoy your own things (Protocol 1, Article 1) and the right to education (Protocol 1, Article 2).



## **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.

Eligibility criteria are a list of rules set by national and local government to say who can get a service and who can't. National government calls this Fair Access to Care.





## 5. Your Services

Service users are not always told who provides and who 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 have the service your social worker offers. Get help from your local service user organisation or brokerage organisation.



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.



## **Getting Involved and 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

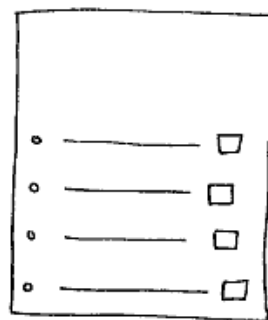
way to change things when a service needs to be made better.

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.

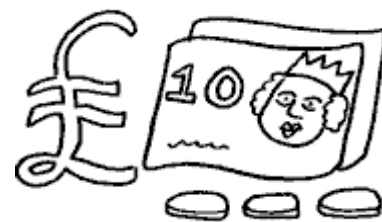


A lot of service users start to get involved when they have a problem that they need to sort out. When they do this they find that there are other ways to get involved as well. Getting involved can be a good way to learn new things, make friends, and talk about things with other people.



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 - your social worker or support worker - 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 - [www.solnetwork.org.uk](http://www.solnetwork.org.uk).



**Shaping Our Lives will be publishing a resource pack for service users and service providers on all aspects of user involvement in summer 2008. 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 will be able to give you a contact in your area.

**National Association for Voluntary and Community Action**

**NAVCA, The Tower**

**2 Furnival Square**

**Sheffield. S1 4QL**

**Telephone: 0114 278 6636**

**Fax: 0114 278 7004**

**Textphone: 0114 278 7025**

**[www.navca.org.uk](http://www.navca.org.uk)**





## 6. 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 contact:

**National Centre for Independent Living**

**4th Floor, Hampton House**

**20 Albert Embankment**

**London SE1 7TJ**

**Telephone: 0207 587 1663**

**Fax: 0207 582 2469**

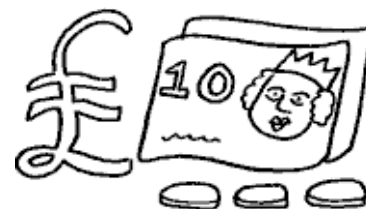
**Text: 0207 587 1177**



**Website: [www.ncil.org.uk](http://www.ncil.org.uk)**  
**Email: [info@ncil.org.uk](mailto:info@ncil.org.uk)**

## Individual Budgets

Individual budgets are another way of getting control over the money for your support. Individual budgets are new but they are spreading across the country.



Individual 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 individual budget for your support comes from different places. You use the money 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](http://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](http://www.disabilityalliance.org)**



### **Benefits Enquiry Line (for disabled people)**

**Tel: 0800 88 22 00**



### **Citizen Advice Bureau**

**contact [www.nacab.org.uk](http://www.nacab.org.uk) to find out local details**



## 7. Your Housing

### What Choices are there?

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**

**Stanelaw House**

**Sutton Lane**

**Witney**

**Oxfordshire**

**OX29 5RY**

**Telephone: (0845) 456 1497**

**Website: [www.housingoptions.org.uk](http://www.housingoptions.org.uk)**

**Email: [enquiries@housingoptions.org.uk](mailto:enquiries@housingoptions.org.uk)**



**Or you can contact Shelter**

**National helpline**

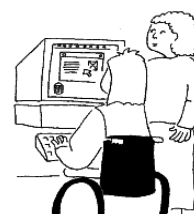
**Telephone: 0808 800 4444**

**Website: [www.shelter.org.uk](http://www.shelter.org.uk)**



**Or from the Citizen's Advice Bureau**

**contact [www.nacab.org.uk](http://www.nacab.org.uk) to find out local details**





## 8. Useful Organisations

### Government Departments

#### Department of Constitutional Affairs

Mental Capacity Implementation Team

5<sup>th</sup> Floor, Steel House

11 Tothill Street

London SW1H 9LH

Telephone: 020 7210 0037

Website: [www.dca.gov.uk](http://www.dca.gov.uk)

Email: [makingdecisions@dca.gsi.gov.uk](mailto:makingdecisions@dca.gsi.gov.uk)



#### Department of Health

This website includes a list of all local Independent Mental Capacity Advocate (IMCA) services.

For more information about what an IMCA is and a list of all IMCA services across the country, contact:

Website: [www.dh.gov.uk/mca](http://www.dh.gov.uk/mca)



#### Valuing People Support Team

For details of regional and national networks for people with learning difficulties and supporters, contact:

Valuing People Support Team

Wellington House (rooms 603 & 604)

135-155 Waterloo Road

London SE1 8UG

Telephone: 020 7972 4036



## **The Equality and Human Rights Commission**

Equality and Human Rights Commission  
Helpline

Freepost RRLL-GHUX-CTRX

Arndale House

Arndale Centre

Manchester M4 3EQ

Telephone: 0845 604 6610

Textphone: 0845 604 6620

Fax: 0845 604 6630

Website: [www.equalityhumanrights.com](http://www.equalityhumanrights.com)



## **Wales**

Equality and Human Rights Commission Helpline Wales

Freepost RRLR-UEYB-UYZL

1st Floor

3 Callaghan Square

Cardiff CF10 5BT

Telephone: 0845 604 8810

Textphone: 0845 604 8820



## **Scotland**

Equality and Human Rights Commission Helpline

Scotland

Freepost RRLL-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

### Shaping Our Lives

National User Network

BM Box 4845

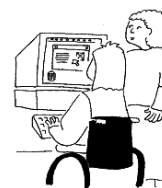
London WC1N 3XX

Telephone: 0845 241 0383

Website: [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)



SOLNET website of organisations of people  
[www.solnetwork.org.uk](http://www.solnetwork.org.uk)



### National Centre for Independent Living

4th Floor, Hampton House

20 Albert Embankment

London SE1 7TJ

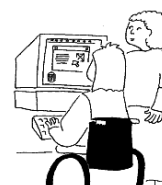
Telephone: 0207 587 1663

Fax: 0207 582 2469

Text: 0207 587 1177

Website: [www.ncil.org.uk](http://www.ncil.org.uk)

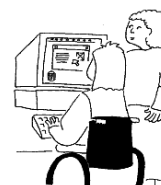
Email: [info@ncil.org.uk](mailto:info@ncil.org.uk)



### Self advocacy

To find your local self advocacy group you can go to the website of the National Forum:

[www.nationalforum.co.uk](http://www.nationalforum.co.uk)



### People First

A self advocacy organisation run by people with learning difficulties based in London is:

[www.people-first.co.uk](http://www.people-first.co.uk)



## Other national organisations

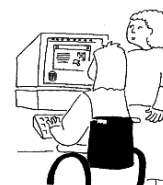
### Values Into Action

Oxford House  
Derbyshire Street  
London E2 6HG  
Telephone: 020 7729 5436  
Website: [www.viauk.org](http://www.viauk.org)  
Email: [general@viauk.org](mailto:general@viauk.org)



### 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  
Website: [www.navca.org.uk](http://www.navca.org.uk)

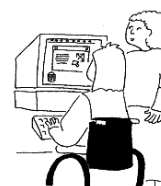


### National Association of Citizen Advice Bureaux

[www.nacab.org.uk](http://www.nacab.org.uk)  
[www.adviceguide.org.uk](http://www.adviceguide.org.uk)

### Housing Options

Stanelaw House  
Sutton Lane  
Witney  
Oxfordshire OX29 5RY  
Telephone: (0845) 456 1497  
Website: [www.housingoptions.org.uk](http://www.housingoptions.org.uk)  
Email: [enquiries@housingoptions.org.uk](mailto:enquiries@housingoptions.org.uk)



## **Shelter National Helpline**

Telephone: 0808 800 4444

Website: [www.shelter.org.uk](http://www.shelter.org.uk)



## **Action for Advocacy**

PO Box 31856

Lorrimore Square

London SE17 3XR

Telephone: 020 7820 7868

Website: [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

## **National Brokerage Network**

3 The Courtyard

Windhill

Bishops Stortford

Herts CM23 2<sup>ND</sup>

Telephone: 01279 504735

Website: [www.nationalbrokeragenetwork.org.uk](http://www.nationalbrokeragenetwork.org.uk)

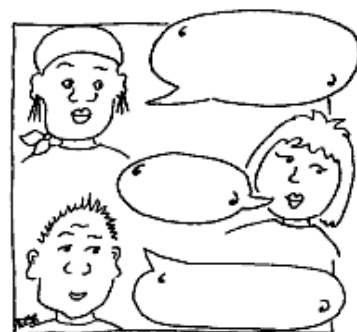




## 9. The Standards We Expect Project

The Standards We Expect project is a research and development project paid for by the Joseph Rowntree Foundation. It started in 2005 and ends in June 2008.

This project is 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?



We 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.

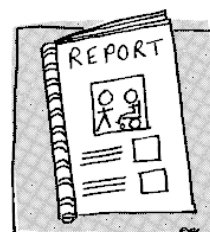
The project was run by a group of four organisations and four individuals, led by Shaping Our Lives, the national service user network. The other partners were Values Into Action, the Centre for Social Action at De Montfort University and the Centre for Citizen Participation at Brunel University.



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



A major book about the project will be published in late 2008. This book will include lots of useful materials, references and contact information.



Other materials produced by the project can be obtained from:

**Joseph Rowntree Foundation:**

Telephone: 01904 629241

Website: [www.jrf.org.uk](http://www.jrf.org.uk)

