

# Family carers matters

Learning disability news and views



## Focus on personalisation

Welcome to the sixth issue of Family carers matters. Unfortunately, in the current financial climate Mencap has had to make changes and this will be the last edition of Family carers matters. Keep checking Mencap's website ([www.mencap.org.uk](http://www.mencap.org.uk)) and Viewpoint magazine for family carers news and updates.

In this issue we focus on personalisation and what it means for family carers. As services become more personal, family carers will have more choice about the support they receive. For some, it may mean providing extra help to the person they care for. We recognise that many families fear change, but personalisation does not necessarily mean taking on more responsibility. You can still opt for your local authority to manage the services you receive.

Our feature on personalisation should help explain how the process works. In this issue we also hear one mother's take on using direct payments, and talk to Caroline Tomlinson about the new shop4support website.

Finally, we would also like to thank all our readers for their support over the past eighteen months.

**Reginald Pobee** (family carer)

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# Personalisation in a nutshell

Samantha Clark, director of Inclusion North, explores the history, the process and the definitions of personalisation



Most people agree that the current system of social care does not work very well. Although we are grateful that good care services and staff are out there, it can still feel like it's not working in the way it should. We want support and services to focus on the wants and needs of the individual. However, they are often designed to meet the needs of many.

The big change in this agenda started with the independent living movement. This was led by disabled people and asserts the rights and citizenship of all people.

The government listened to what people were saying, and said that the way social care worked for adults had to change. It is not just about how specialist services work, but also how people can become full and active members of their local communities.

This agenda has become known as personalisation – a promise to change

how social care and all mainstream and community services work, based on a commitment to independent living for everyone. The agenda sets out a shared set of values from local and central government, along with agencies such as the Association of Directors of Adult Social Services.

The government paper on personalisation was published in December 2007. Putting People First says that local and central government must work together to make this 'the first public service reform programme which is co-produced, co-developed, co-evaluated and recognises that real change will only be achieved through the participation of carers and users at all levels.'

## Handy definitions

### **Personalisation**

Support and services should be tailored to the needs of the individual, rather than the individual fitting in to existing services.

### **Self directed support**

An individual takes control in deciding the support they need and how it is delivered and paid for.

### **Direct payments**

A means-tested payment to an individual assessed as needing support. The money is paid by the local authority social services department. Direct payments specifically buy social care services.

## Individual budget

A budget that can be used to buy a range of services (not just social care). Comes from a number of different sources.

## Personal budget

Originally a term used to describe the amount of social care funding an individual was receiving, but now used to describe the same thing as the term individual budget.

## Resource allocation system

The way of calculating the amount of money an individual needs to buy enough support.

## In Control

In Control is a social enterprise that has worked to introduce self-directed support since 2003. Below is their seven step guide to using individual budgets.

The steps involve a radical but positive rethink of the existing care management service.

Some people choose to keep their current services, some people change part of their support and others make more radical changes.

Lots of people who tried individual budgets found they got the support that makes sense to them, and the life they want to lead.

<b>1. Set individual budget</b>	A person is told how much they can expect to receive based on a simple assessment.
<b>2. Plan support</b>	The person plans how to spend their money.
<b>3. Agree plan</b>	The plan is agreed with the local authority, who appoints an agent if needed.
<b>4. Control individual budget</b>	The person takes as much control as they want over their money and services.
<b>5. Organise support</b>	Money is used to buy services and support. Help is available if needed.
<b>6. Live life</b>	Money can be used flexibly to achieve real outcomes that make a positive difference.
<b>7. Review</b>	The person tells their local authority how it has gone and what they are going to do next.

 You can find out more by contacting your local self-directed support or personalisation leads via your local authority. Or you can go to [www.in-control.org.uk](http://www.in-control.org.uk) or [www.tinyurl.com/dhpersonalisation](http://www.tinyurl.com/dhpersonalisation)

# A direct relation

Direct payments allow people to buy their own support. For many family carers, this means taking on the management of staff. But becoming an employer can be a daunting task



Rachel Walker has two sons – William, 9, and 10-year-old James, who is severely autistic with a moderate learning disability. For the past three years Rachel has received eight hours' help per week via direct payments, and she would urge others to consider doing the same.

In November 2004, Rachel was told that as James had no outstanding medical needs, he would be discharged from hospital care. Rachel, having voiced her concerns on this, was then referred to social services for a respite assessment.

In June of the following year a social worker finally made an assessment of the family's needs. It was then that the social worker first mentioned direct payments and wrote an initial report. Following that, a final local authority

agreement in February 2006 agreed to Rachel's request for eight hours of help per week.

Rachel admits that finding personal assistants can be difficult, and her top tip is to consider employing learning support assistants or teaching assistants. She also uses her payments to fund charity play-schemes or after-school clubs, and Rachel has also been able to 'employ' members from these clubs.

Overall, and despite the time it took to get them, Rachel's experience of direct payments has been very positive. The payments have allowed Rachel the time to be mum to William as well as James, and have given the family the support they need to cope.

"Although it was a long process getting direct payments agreed for my particular family needs, the

last three years have enabled me to use the service very effectively while also in a flexible way," said Rachel.

"Direct payments have been invaluable to our family."

## Rachel's tips for using direct payments

- Don't panic!
- Record everything relevant in a notebook.
- Register with HM Revenue & Customs (HMRC) as an employer.
- Register those you want to employ as personal assistants.
- Get Employer Liability Insurance.
- Get Criminal Records Bureau (CRB) checks for employees. (Harrow Council wouldn't begin direct payments until it had received these.)
- Get a receipt book.
- Choose to pay with either cheques or a debit card.

# Personalisation – the Mencap position

Campaigns and policy officer Rossanna Trudgian explains Mencap's take on personalisation



Many family carers have found that personalisation has improved the quality of life of their loved one. Sadly, this has not been the case for everyone. Mencap recognises that the current system has major flaws. We have worked closely with family carers to understand their issues and raise them at national level.

Many of the weaknesses are a result of poor implementation by local authorities. Each is responsible for introducing

personalisation to the local area. Some have brought it in throughout their services, while others have failed to do anything. Mencap has called for urgent action to resolve this.

## Family carers' rights

Family carers have said that personalisation puts pressure on them – particularly if the people they care for use individual budgets or have profound and multiple learning disabilities. Mencap strongly believes that the rights of family carers must not be overlooked. We have campaigned to relieve the pressure on these family carers, calling for short breaks and more support.

Lots of family carers have problems with personalisation during the planning stages. Before someone receives personalised care, a person-centred plan sets out the person's aims and the care package they

need to achieve this. The person and their family should be at the centre of this process. Mencap is aware that this has not happened for everyone – we strongly believe that it is essential to involve families.

Finally, the government has always said that, for personalisation to succeed, individuals and their families need to receive information, advice and support from local authorities. Again, this is not happening everywhere.

Mencap continues to support personalisation but will also fight to ensure that the positive aspirations are not lost in its implementation. Working in partnership with a variety of other charities, we have called for the Department of Health to step up and deal with the system's weaknesses.

 **Go to [www.mencap.org.uk/personalisation](http://www.mencap.org.uk/personalisation)**

# Making it happen for carers

The personalisation of social care services is great for people with a learning disability. But it also benefits carers, as the Department of Health's Bernadette Simpson explains



Putting People First is the government document that is guiding the personalisation of adult social care. It gives people greater choice and control of local support and services so they can live their lives as they wish. Importantly, it must be implemented in a way that supports and includes family carers as partners and contributors.

For local authorities, there are very close connections between the Putting People First themes and the outcomes of the carers' strategy.

Personalised approaches help ensure that carers are respected, treated with dignity and have a life outside caring. Making the changes in adult social care that are 'carer friendly' requires a whole system that thinks about the impact on carers – remembering they have a legal right to a carer's assessment and looking at their aspirations for work, training and leisure activities.

## **Bringing together Putting People First and the carers strategy**


The Department of Health, the Association of Directors of Adult Social Services and national carer organisations ran three national workshops in June to support local authorities to explore the links. The workshops brought together local teams of people who are responsible for delivering change for carers. They will start to explore different models of delivery and examples of

good practice.

Early research has shown that personal budgets and self-directed support can have a positive impact on carers' quality of life and social care outcomes. Carers say they appreciate the greater flexibility, choice and control. It can improve the wellbeing and quality of life of the person they are caring for and enhance family relationships.

The workshops aim to identify the challenges and solutions emerging across the country so we can work towards improving support for carers.

Following these events, the intention is to provide information, materials, and examples that local authorities and their partners will find useful.

 **For information on Putting People First and the impact on carers go to [www.nds.coi.gov.uk](http://www.nds.coi.gov.uk)**  
**For information about the carers' strategy go to [www.dh.gov.uk](http://www.dh.gov.uk)**

# Family talkback: personalisation

Caroline Tomlinson is the Consumer Support Director at in Control. She is also mum to three children, including 19-year-old Joe, who has high support needs and was the first person in the UK to receive an individual budget

## What does personalisation mean to you and your family?

It means living life as a real family. I have become a parent again rather than being a 'carer'. Joe just happens to have a team of personal assistants who support him to live his life.

## How has the process been?

It's been a positive process with a real tangible outcome. Most of my experiences in the past have been time consuming with often no positive result. Life isn't by any means perfect – but whose is? Having a personal budget is just part of our day-to-day responsibilities that we make work for us in the widest possible sense.

## What are the pros and cons?

Joe now has his own home, car, business and support team – what more

could we ask for? If I were to change one thing, I would push for wider choice and control in health services. For example I would give us a personal budget for continence supplies – it's an unnecessarily highly regulated and overly controlled service.

## What are your tips for families who want to personalise services?

Contact other people who have already been through the process, watch DVDs and read stories. Go to [www.in-control.org.uk](http://www.in-control.org.uk) and watch out for the launch of shop4support ([www.shop4support.com](http://www.shop4support.com)) at the end of 2009. Don't wait for your local authority to offer you a personal budget – start demanding one.

## What is shop4support?

It's a website that lets you find services and information in your area. You can develop a support

plan, buy support services and manage your budget.

## How can families find out more about personalisation in their local area?

Contact your local authority to speak to the person leading on personalisation. If this doesn't work, contact the in Control support centre on **01564 821 650** or [admin@in-control.org.uk](mailto:admin@in-control.org.uk)



# In brief

The government is making changes in the Equality Bill in an attempt to end discrimination against carers. The changes will protect people who are 'associated with' someone who is disabled. This will apply to employment and the provision of goods, facilities and services.

**Go to [www.equalities.gov.uk](http://www.equalities.gov.uk)**

Carers' Week took place in June with the theme 'Carers... the UK's secret service'. The campaign focused on better support and recognition for carers.

**Go to [www.carersweek.org](http://www.carersweek.org)**

Opinion Leader, a research-based consultancy, is looking into the needs of adults with autistic spectrum conditions (ASC). It will then feed its findings into a government consultation on the issue. Opinion Leader is looking for people with ASC, their family carers and professionals to share their experiences. Group discussions, online forums and one-to-one interviews will take place from Monday 29 June to Friday 17 July 2009.

**Go to [www.oladultautism.org.uk](http://www.oladultautism.org.uk) or call 020 7861 2877**

'Recognising Fathers: a national survey of fathers who have children with learning disabilities' is a new report from the Foundation for People with Learning Disabilities on the involvement of fathers in their child's upbringing. It describes how many fathers want to be more involved in a child's upbringing, but practices in health and social care and employment focus primarily on mothers. This often leads to fathers struggling to combine their caring roles with employment, and to stress-related illness. The report argues that the involvement of fathers can benefit the whole family and makes recommendations to achieve this. **To download the report go to [www.learningdisabilities.org.uk/fathers](http://www.learningdisabilities.org.uk/fathers)**



## In Control and Me

The in Control and Me advice project is in its second year. It was set up to consult people on existing information about self-directed support and also to produce useful accessible information.

The project has produced factsheets on various areas of self-directed support, which will be put on the in Control website in autumn 2009.

Mencap's helpline advisers took part in self-directed support training in June 2009 and will be taking enquiries on this subject from autumn 2009. This service will also be launched on the in Control website. You can contact Mencap's helpline advisers on **0808 808 1111**

**Go to [www.in-control.org.uk](http://www.in-control.org.uk)  
To order a factsheet, email [lisa.dunne@mencap.org.uk](mailto:lisa.dunne@mencap.org.uk)**