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# What do people labelled with learning difficulties think about their access to direct payments?

Direct payments are becoming increasingly important in arranging services for people with learning difficulties, but what do they think about their access to them?

By the Carlisle People First Research Team. The team has been working together for 12 years and currently has eight members. Five members share the label of 'learning difficulties'. The main purpose of the team is to carry out work that is of benefit to people with learning difficulties and not to reject anyone. In this project the researchers were John Dias, Louise Townson, Elizabeth Harkness, Malcolm Eardley and Chloe Brownlee-Chapman.

There is evidence from a range of sources that people labelled with learning difficulties, in using direct payments, are able to take more control of their lives. But the Carlisle People First Research team, through contacts in self advocacy groups, have heard a number of stories from colleagues about difficulties faced in accessing direct payments. We felt it was an area we wanted to explore.

The team were commissioned by the Disability Association of Carlisle and Eden to undertake a research project on finding out about people's views. We would like to acknowledge the warm support of Fred Wilenius and DACE (Disability Association of Carlisle and Eden), based in Cumbria.

The growing importance of personal budgets and the option of direct payments is, we believe, a good thing. But a lot of people who have the label of learning difficulties may have to take on a bigger role

in understanding, organising and managing their own care. The choices involved in this can be difficult, and we hope professionals can listen to some of the concerns people feel about their access to direct payments.

## Background information

As with all of our research projects, the research question was broken down into eight main parts, a process the team had developed in 2001 (Carlisle People First, 2001).

At the start of the project we looked into what information was already available to people about direct payments and how useful this information was. We read (and listened to others reading) a number of documents published by the Department of Health and information that was available through social services and local organisations. We also watched the 'Direct Payments Show' video and other audio visual information.

In doing this we discovered that the information available did not include many of the views of people labelled with learning difficulties. We found the information was mainly aimed at carers and social workers and was therefore written from their point of view.

In talking directly with people labelled with learning difficulties we found that many people did not know what a direct payment was. This is not surprising as figures show that in 2007 only 84 direct payments were available to people labelled with learning disabilities across the north-west region (PSSRU, 2007). Now there are 152 out of 1,232 adults known to services with the label of learning difficulties in Cumbria receiving a direct payment (DACE, 2011). Clearly there has been some improvement but take-up is slow.

## Methods used to set up the project

To understand more about direct payments take-up we decided to collect the views of adults of different age groups from all over Cumbria. We spoke to 108 people labelled with learning difficulties in Cumbria living in different areas across the county. We asked local support workers of the People First speaking-up groups in Barrow, Workington and Carlisle to work with their groups and collect

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## The research cycle



responses. We thought it was important for questions to be asked by people who knew the respondents very well.

We used different methods to collect information so that we could address diversity of support and communication needs. In our guidelines for working we need to ensure our methods of research are accessible. Some people prefer to give information in different ways than others.

The different methods we used to collect information from people were:

- Word shower: This technique was used at a formal meeting so that we could get initial ideas about what people thought about direct payments in general

- Role play: This was used at a more informal group meeting with people who knew each other quite well. We asked two people to take on the role of interviewing for supporters and two others to take on the role of applying for personal assistant posts. We explored ideas of good and bad support. We then recorded the discussion that took place

- Focus groups: These meetings were organised with a guest speaker who gave a talk about direct payments. We followed this with discussion to explore what people

did or did not know about direct payments as well as and what people had thought of the presentation

- Body shapes: We used 'body shapes' at a group meeting where the outline of the body of someone in the group was drawn around and the shape was then filled with statements of what people thought. We used the body shapes to help us discuss good and bad support

- Group discussion: We asked local supporters to hold discussions with their groups around Cumbria. We felt this would be better for the groups involved as familiarity with people is something we think is very important
- Direct payments diary: We asked people who were applying for direct payments if they could keep a diary of their experiences of the process.

## Findings

We learned a lot about what people labelled with learning difficulties thought about direct payments. As the research had used a lot of different methods, we found that we could place the findings under an 'umbrella of ideas' in order to group the issues into different themes that emerged as important to people.

The umbrella allowed us to show that there were some overarching ideas about direct payments which

sat above a lot of smaller issues. This was a strong picture which people were happy to use because it made the research very clear and therefore easy to understand.

### 1. Views on direct payments

We found that out of the group of 108 people labelled with learning difficulties, most did not really know, remember or were clear about what direct payments were until the information had been given.

Some examples from the word showers and comments have been included below:

- Independence
- Power
- Complicated
- Helps to get a job
- Don't know
- Budgeting
- Use it or lose it
- Not everyone can have one
- Assessments
- I want to know more about direct payments
- Won't interfere with my benefits
- Will interfere with my benefits
- About paying for things
- Can't remember
- Heard of it
- Sounds familiar but not sure
- If you don't use direct payments properly you lose them
- I know about direct debits
- Nothing has been said to us at the daycentre
- Only certain people get them

### 2. What support is needed to get a direct payment?

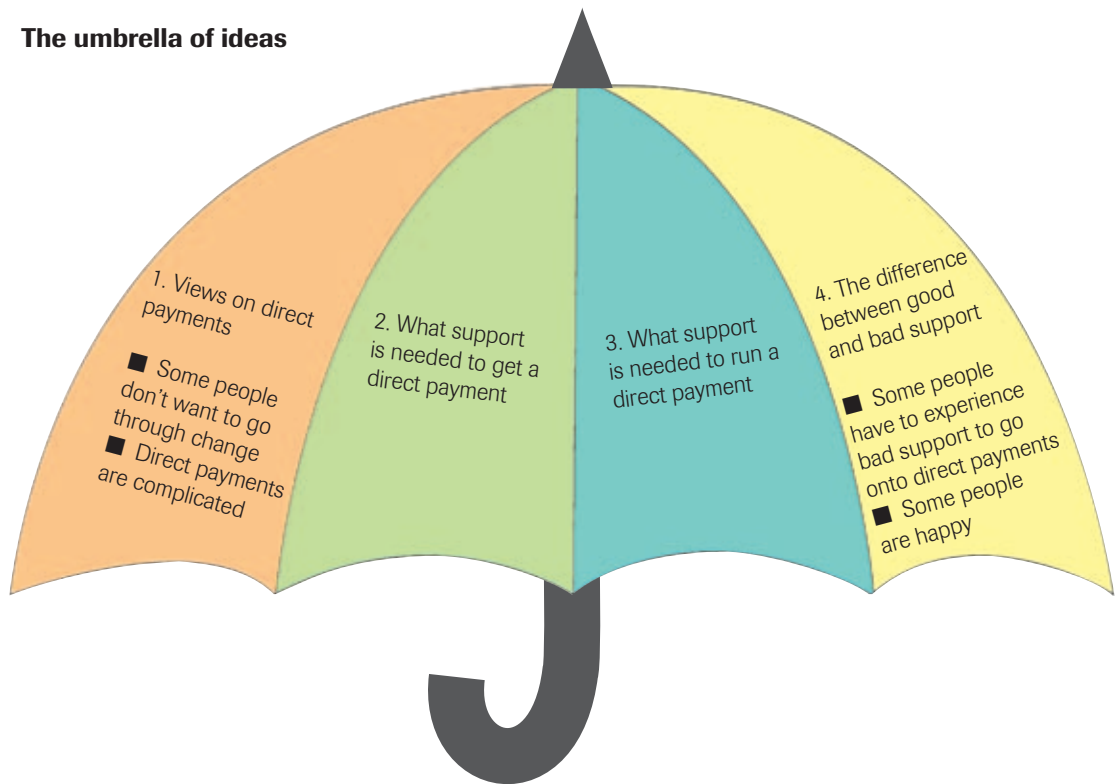
This theme was divided into two. First of all people spoke about who you would need to get in touch with to apply to access a direct payment:

- Key workers
- Social workers
- No idea

The second theme under this topic was about where people would get their own support from to access a direct payment:

- People First
- Social worker
- Staff at day centres
- Community nurse

## The umbrella of ideas



- Family
- Anyone
- Don't know

3. The third major theme was about what a direct payment might pay for along with who would help with that support:

- Holiday support
- Shopping
- Staff
- Getting my own support
- Carers
- Disabled badge
- Taxis/transport
- Don't understand
- Don't know

4. Finally the information we gained helped us to understand what people labelled with learning difficulties thought was good or bad support and how important that might be. We came up with a number of sections here.

What people think good support is?

- Enthusiastic
- Explain things
- Experience
- Give advice
- Do what we want not what they want
- I'm in control
- Let me take risks

- Take me on holiday
- Listener
- Good sense of humour
- Someone who can drive
- Flexible

What people think bad support is?

- Rules and regulation
- Organising your life without you
- Swearing and bullying
- Risk assessments
- Doesn't turn up
- Bad time keeping
- Stealing
- Ignores me
- Not being believed when something bad happens
- Treat us as adults not children
- Being told your life is none of your business
- Doesn't listen
- Coming into my house when I'm not there
- Carers changing over without asking

Who people think they can have supporting them.

- Whoever I want
- Key workers
- I will employ people
- Carers
- Day centres

- Social workers
- I don't know

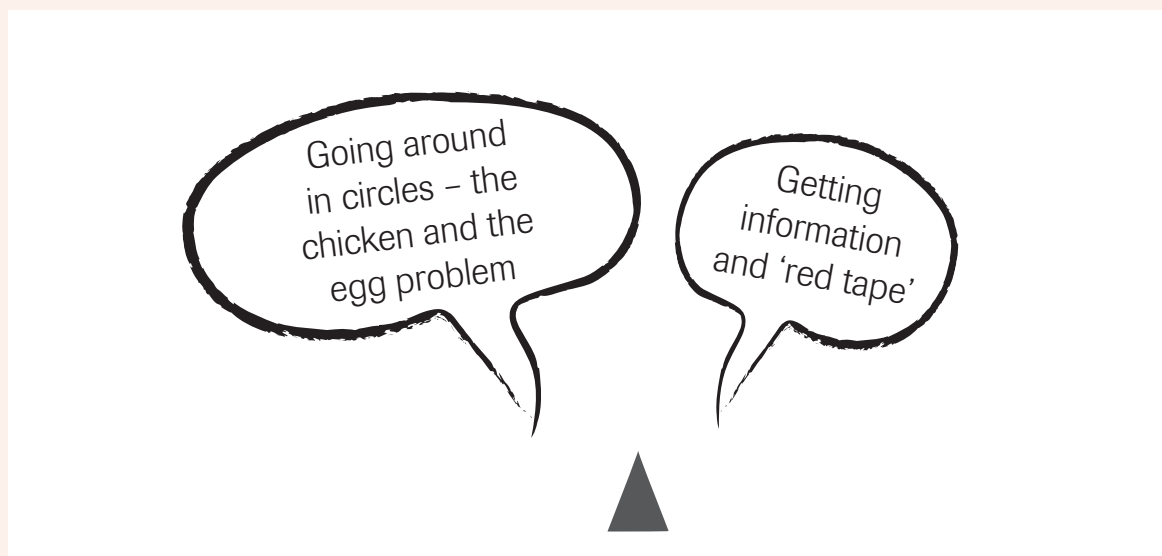
How important people think that support is when they think about direct payments.

- We are inviting people into our homes
- Only worth it if you get good support
- They need to be open to learn from people with learning difficulties
- Bad support is why I want direct payments
- It's more important to have someone with the right attitude rather than someone who had been working with people with learning difficulties for a long time because sometimes they get caught up in all the red tape.

## Discussion

We looked at everything we had learned to try and work out what the main issues were about people's feelings about accessing direct payments.

There were difficulties in getting information. Direct payments were felt to be very complicated and hard to understand. Clearly there were a number of people who were



viewed as being able to help with accessing information or running a direct payment but it might have been helpful if there was more clarity or someone with a definite role that people could be informed of.

It emerged that people found it difficult to know that they really needed to find out the relevant information. We called this 'the chicken and egg' problem, or, how do you know that you need to know what you don't know? This rang true for support as well. In order to get a direct payment you needed support. But often it was difficult to access that support unless you already had a direct payment. These problems are the spiky point of our umbrella (see diagram above).

The problems were explained really well by one person's diary entries: "In August I started to enquire about getting a social worker (and to find out about access to a direct payment). I was told there was a waiting list so it was a case of waiting. In the November I kept ringing social services to see what was happening. I felt that I was getting nowhere and it was very frustrating. Mam agreed to contact them and she was told that I would get a social worker within two to three weeks which didn't happen. In the following January the person we had been dealing with went on sick leave so I spoke to someone else. It turned out nothing had been done at all and Mam and I were furious because we felt like we had been ignored. I then had to

go through an assessment to see whether I met the criteria for a learning difficulty or physical disability social worker. I was finally allocated a social worker in the June."

Time delays are frustrating, especially when there are a list of things you have to get put in place before you can get assessed and then see if you are able to get a direct payment.

Another interesting point was a discussion where people were very confused between what a direct debit was and what a direct payment was. People in the discussion found it was hard not to get these two mixed up. There was also a discussion about the 'red tape' involved, the amount of paperwork to be dealt with and figuring out where and who to go to. This could be off-putting. Some people dreaded the responsibility of having a large amount of money in their bank accounts to deal with. However some people thought that it was important that people were allowed to make mistakes.

It was interesting that people felt very strongly about direct payments and what they thought they were. We also thought that it was quite sad that some were only really interested in getting a direct payment after bad experiences in their present services. It was said that new supporters are often better because they are not caught up in issues from the past and the red tape.

Overall, the people we spoke to did think that having more power

and independence was a good idea but interestingly they didn't feel comfortable enough to use this as a reason to ask to go onto a direct payment. We wondered if this was because people did not want to hurt the feelings of those already involved in providing support, or if they were reluctant to 'rock the boat'.

In terms of support the message we got was that people really did not seem to be too interested in where the money for their support came from; they were more interested in what the supporter would be like.

Of the people that did already know about direct payments, the majority had found out through the work of People First. We wondered if this is because People First has run sessions over the years about direct payments – what they are and how to get them.

This means that people labelled with learning difficulties in People First groups in Cumbria are getting more information about direct payments than those who aren't.

## References

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