

## The importance and availability of peer support for people with learning difficulties accessing direct payments

New regulations which came into force in 2003 in England (and similar measures in Wales in 2004) mean that local authorities do not just have the power to offer direct payments; they now have a duty to offer them to eligible people. In theory, this should mean far higher numbers of people receiving direct payments, including people with learning difficulties. But key to take-up of direct payments is the availability of effective support to access and manage them. Research by Values Into Action looked at the availability of peer support for people with learning difficulties. The researchers found:

-  There are very few independent direct payments support schemes run by and for people with learning difficulties.
-  Most independent direct payments support is provided by existing disabled people's organisations or direct payments schemes set up for the purpose.
-  There are some very good examples but most independent direct payments support schemes have limited or no involvement by people with learning difficulties.
-  There are different views and expectations about what 'independent' support means.
-  The quality of support is crucial, not just its independence from statutory services.
-  Assumptions about consent and ability to manage direct payments can block people with learning difficulties from accessing support and these can be held equally by independent support schemes as by statutory services.
-  Sometimes an individual with appropriate attitudes, information and experience, whether based in independent support agencies or within social services, can have more effect in enabling people with learning difficulties to access direct payments than an independent contract that is given to those with little knowledge or experience about including people with learning difficulties.
-  Local issues and assumptions around funding, tendering and contracts have a big influence on whether people with learning difficulties are included in support schemes and whether contracts are given to groups of people with learning difficulties.

## Background

Many researchers and national commentators have emphasised the importance of good independent support to enable all sorts of people to access direct payments. This view is also reiterated by the Government:

**“Experience has shown that developing support services is a key element of successful implementation of direct payment schemes.” (Department of Health Guidance, 2003)**

But there are different views and models for what this support should be like, who should provide it, how it should be paid for and managed, and who it should be aimed at. There are also different interpretations about what ‘independent’ support means.

A logical step is for people with learning difficulties to run properly funded independent peer support schemes or agencies to offer advice, information, support and inspiration on a more organised basis. However, the involvement of people with learning difficulties as the *givers* of advice and support around direct payments seems limited. This research aimed to find out if this impression is the case, if it is then why, and if it isn’t, then what examples of good peer support can be found.

## What is peer support?

The research’s starting point was to look at direct payments support that is:

- *independent* of statutory services; and
- *run by* people with learning difficulties.

It was also assumed that such a support scheme would be funded, either in a contract from social services or by some other means and would be likely to be attached to a self-advocacy group.

The research was only able to find one example that fitted the above model of independent peer support. So, the next layers of independent support were included:

- Support given by and for people with learning difficulties not as a contracted independent service but in a more individual and informal way. This might include self-advocacy groups offering informal information and support on direct payments.
- Support given by an independent disabled person’s organisation. This support is independent of statutory services and offered by disabled people but not specifically people with learning difficulties.
- Support given by an independent direct payments agency. This support is independent but unlikely to be run by disabled people, although disabled people may be on management committees.

## What support is needed?

On the whole, people with learning difficulties need exactly the same sort of information, support and advice as other potential direct payments users, that is:

- information;
- support in accessing direct payments;
- support in managing them, including payroll, managing staff etc.

However, they may need this support provided in a different way (for example, written information may not be so useful or timescales for discussions and decisions may need to be longer). They also often have the hurdles of assumptions around consent and ability to manage a payment to overcome too.

## The importance of peer support

These issues can affect the content, style and process of support which an organisation needs to offer to fully include people with learning difficulties. This research found a limited picture of direct payments agencies adapting what they do to meet these needs.

## Response from local authorities

The research showed that even with a support organisation providing good support, the number of people with learning difficulties accessing direct

payments was still greatly influenced by the attitude and approach of the local authority and staff. Many research participants experienced resistance to people with learning difficulties accessing direct payments at some level within their local authority. Some thought that frontline staff were positive and effective in relation to direct payments, while those controlling budgets and in more senior positions got in the way. Another support organisation took the opposite view, saying there was a champion at senior level but the front-line workers were putting obstacles in people's way. None of the interviewed organisations were entirely positive about the local authorities they worked with and some were very negative.

Some of the reasons given for this negative response by local authorities were:

- reluctance on the part of the local authority to accept that people with learning difficulties should have access to direct payments;
- a belief that the local authority would be unable to cope with increased take-up if they promoted direct payments;
- a worry that the support organisation would ask for more funding to cope with increased demand from potential direct payments users;
- worries about implications for local authority budgets and operations, especially considering current investment in existing systems and structures;
- few demands being made by people with learning difficulties, individually or collectively, because they had no strong voice in specific locations.

None of the support groups researched believed that they were funded adequately by their local authority to offer effective and responsive services to all groups in their area who might want a direct payment.

In addition, contracts and tenders tend to be awarded for work with the biggest numbers of people for the least possible amount of money. This approach does not support the individual needs and potentially different approaches that could be taken with people with learning difficulties.

## The involvement of people with learning difficulties in running peer support

All the support organisations participating in this research had disabled people as staff or trustees and some were wholly run by disabled people. However, only one support organisation was run by people with learning difficulties and only two of the others in which disabled people were involved also included people with learning difficulties in running the organisation.

The reasons offered for this were beliefs that:

- The group lacked the expertise or experience to work with people with learning difficulties.
- The needs of people with learning difficulties were very different to those of other members of the group.

Both these reasons say more about underlying attitudes and experience than real difficulties. Those support organisations that have included people said that people with learning difficulties do not need different advice and information but may need it presented in different ways.

## Conclusions

There is little independent direct payments support run by and for people with learning difficulties. However, the research has also found that people with learning difficulties, especially those receiving a direct payment, have a unique role to play in informing and inspiring other people to apply for direct payments. However, this championing role must be mirrored by an equally effective commitment to direct payments within the local authority so that those who have been inspired to apply for a direct payment are actually enabled to get one.

This research has shown that flexible, person-centred, creative ways of outreach, information provision and work achieve best results in getting people with learning difficulties onto direct payments.

Independent support organisations coming out of disabled people's organisations need to ensure that they are not replicating the barriers to direct payments for people with learning difficulties which local authorities have.

Peer support does matter. It is about creating a local and national community of disabled people, including people with learning difficulties, who are experienced and expert in direct payments, who can inform and support others to access direct payments and, very importantly, who can inspire others to see that choice, control and opportunity in their own lives is possible.

### About the project

The research took place between April 2003 and June 2004. Sixteen organisations were interviewed either by telephone or face-to-face, to gather details. These were:

- 1 Social Services Department;
- 3 self-advocacy groups;
- 6 Centres for Independent Living;
- 6 other support organisations run by disabled people.

### How to get further information

For further information on this research or VIA's work on direct payments, contact Linsay McCulloch, Deputy Director at VIA at the above address or on 0207 729 5436.

The full report, **Helping ourselves: Direct payments and the development of peer support** by Catherine Bewley and Linsay McCulloch, is published by Values Into Action (price £9). Copies can be ordered:

- in writing from: Values Into Action, Oxford House, Derbyshire Street, London E2 6HG;
- by fax: 020 7729 7797;
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