

Direct payments for people with learning difficulties

The Community Care (Direct Payments) Act 1996 came into force on 1 April 1997. It empowers local authorities to make cash payments to people with disabilities, including learning difficulties, for the purchase of their community care arrangements. People with learning difficulties and their supporters are already recognising the potential benefits, but few preparations have yet been made, according to recent research undertaken for Values Into Action by Jean Collins, Andrew Holman, Simone Aspis and Yve Amor. The study, which interviewed people with learning difficulties, support schemes and local authorities, found that:

-  Many independent living schemes had supported people with physical or sensory disabilities to use indirect payments, but comparatively few had experience of supporting people with learning difficulties.
-  Some local authorities were assuming that there would be no demand for direct payments from people with learning difficulties. However, people with learning difficulties were often enthusiastic about direct payments once they knew about them.
-  Local authorities differed widely in their interpretation of a person's capacity to consent to a direct payment; some did not take into account the role that could be played by assistance and support in communication.
-  Some local authorities were daunted by the prospect of setting up a new system to handle direct payments and had adopted a 'wait and see' approach in order to learn from the experiences of others.
-  People with learning difficulties and local authority staff agreed that continuing support will be needed to enable people with learning difficulties to use direct payments successfully. Local authorities also felt development work with people with learning difficulties and their supporters to be a necessary initial step. However, all the local authorities interviewed pointed out that no additional funding has been allocated for development work, or for the operation of support systems.

Background

Prior to the implementation of the Community Care (Direct Payments) Act 1996 on 1 April 1997 it was illegal for local authorities to make cash payments to people with disabilities *in lieu* of providing community care services. However, a number of local authorities were supporting over 60 Independent Living Schemes, Personal Assistance Schemes and Centres for Independent Living, in addition to an unknown number of Service Brokerage schemes and individualised trusts. In a variety of ways these handle community care payments on behalf of disabled people, and provide the advice and assistance that many disabled people need in organising their assistance or support.

The Community Care (Direct Payments) Act 1996 builds on this existing situation. As with indirect funding, a direct payment takes the place of community care services that would otherwise be provided by the social services department.

This study shows that some people with learning difficulties already have valuable experience of using indirect payments, but that many are unaware of the possibilities; while local authorities range in attitude from those who welcome the legislation to those who remain cautious.

Present experience

Most of the people supported by existing independent living schemes have physical impairments, although some schemes do also support people with learning difficulties. The kinds of assistance provided by the schemes include helping people consider what they want and need, and helping them organise and manage their support.

Some people with learning difficulties already use individualised trusts to handle cash payments. A trust is a legal structure which manages a person's money on their behalf. People involved in trusts regard these as particularly useful for people with higher support needs since they provide both a legal framework to ensure that any questions of employment or other liability are met, and a quality framework to provide safeguards and ensure that the desired support is delivered.

Not everyone with learning difficulties who is currently receiving cash payments is either using a support scheme or has a trust. It is therefore likely that some people will want to deal with their direct payments themselves, without the involvement of additional support systems.

Some people with learning difficulties already use service brokers to help them identify and access the services they want. This research demonstrated that some brokers have developed considerable expertise in supporting people with learning difficulties appropriately in the assessment, design and implementation of support packages, as well as providing them with advocacy. Several people suggested that people with these skills will be particularly effective in enabling those with greater support needs to use direct payments. One social services manager commented that service brokerage offered:

“All the advantages without the risks”

because it facilitates access to the desired support while safeguarding the person's interests.

Information and demand

Most of the people with learning difficulties interviewed in the research had not heard about direct payments. Nevertheless, many were easily able to think through the potential benefits. One person, for example, thought that direct payments could lead to:

“... more independence, greater privacy, more friendships and going to places I want to go to.”

Several people also recognised that direct payments might have disadvantages, such as:

“...choosing the wrong workers, not knowing how to budget and lack of information about how to employ workers.”

Despite these potential problems people with learning difficulties were generally keen to investigate direct payments further. They pointed out that they would need support to help them decide whether to accept a direct payment, as well as support in setting up and operating their chosen arrangements. They also noted that other people around them might find it difficult to accept such changes. As one person said:

“My parents need support with letting go of me.”

People with learning difficulties also said that information about direct payments needed to be made widely available in accessible formats, using pictures, simple text and audio and video tapes.

However, the research discovered that in many cases local authority views on the information they should provide, and on how people with learning difficulties would respond to direct payments, were very different from the views of people with learning difficulties themselves. One local authority acknowledged that they were:

“not very good at getting messages across”

and several authorities doubted that there would be any demand for direct payments from people with learning difficulties. The research indicates that without accessible information people with learning difficulties are likely to remain in ignorance of direct payments, and will in that case not be in a position to ask for them.

Assessment and consent

The research revealed that local authorities differ widely in their interpretation of a person's capacity to consent to a direct payment. Some authorities consider that the key is whether the person has the ability, with assistance, to use and control the direct payment successfully. This accords with the research finding that, where people with learning difficulties who have very high support needs are already using cash payments, the system of support created around them ensures that they are in control.

Some other authorities are disregarding the fact that people with learning difficulties can be assisted to communicate decisions they may be able to make, and are instead assuming an inability to consent. Such an interpretation would debar from a direct payment some people already receiving cash payments. It would also exclude a significant number of disabled people from legislation intended to benefit them.

Issues of gender and culture

The research found very few women with learning difficulties or people with learning difficulties from black or minority ethnic groups currently using cash payments. In view of the small size of the research sample, it is not clear whether this finding is typical: if it were, it would suggest that special attention will need to be paid to ensure that women with learning difficulties and people with learning difficulties from black or minority ethnic groups are made aware that direct payments offer opportunities for increased

independence and self-determination, and more appropriate, individualised forms of support than may be offered by existing mainstream services.

Initial and continuing support

The research found widespread agreement amongst people with learning difficulties and local authorities that continuing support will be needed to enable people with learning difficulties to use direct payments successfully. Local authorities also agreed that development work with people with learning difficulties, their allies, supporters and staff is a necessary initial step in the development of direct payments systems.

However, all the local authorities interviewed pointed out that no additional funding has been allocated for development work, or for the operation of support systems in either the short or long term. One manager stated that this meant they would have to:

“... stop doing something old to do something new.”

Despite this, some local authorities already have advance plans for the development of direct payments, including Development Officers in post. The problems associated with 'double funding' of services while old and new systems necessarily run side by side were not seen by these authorities as insurmountable. Nor did these authorities consider that making direct payments to people with learning difficulties would undermine the continued provision of existing services for other people.

About the study

These findings are the result of an initial study of direct payments following the passing of the Community Care (Direct Payments) Act 1996. Between January and March 1997 researchers interviewed people with learning difficulties in 6 localities, senior managers in 6 local authorities and 6 independent living support schemes, across England and Scotland.

Further information

A detailed report from the research, which incorporates recommendations for the implementation of direct payments for people with learning difficulties, has been published by Values into Action (VIA), under the title Funding Freedom. It is available from VIA, Oxford House, Derbyshire Street, London, E2 6HG, at £7.95 plus £1.50 postage and packing.

A Plain Facts and audio tape summarising the research for people with learning difficulties and their supporters and suggesting further action is available from the Norah Fry Research Centre, 3 Priory Road, Bristol, BS8 1TX. Tel: 0117 923 8137.

Further information may also be obtained from Jean Collins at VIA, Tel: 0171 729 5436, or from Andrew Holman on 01638 552703.

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