

Direct payments for young disabled people

The Carers and Disabled Children Act 2000 extended access to direct payments to 16- and 17-year-old disabled young people. A project carried out at the Norah Fry Research Centre, University of Bristol, sought to collate the work going on in this area; to highlight the main issues facing young disabled people who would like to access direct payments; and to produce a resource with and for young disabled people to promote take-up. Key findings were:

- f** The extension of direct payments to 16- and 17-year-olds aims to provide opportunities for young disabled people to increase their independence and choice.
- f** Some young disabled people saw direct payments as a potentially significant means to achieving greater autonomy and control but they were also concerned about the obstacles they would confront in trying to access them.
- f** There are a number of potential barriers to the successful take-up of direct payments for young disabled people. These include young people's lack of knowledge about direct payments.
- f** Social services departments have concerns about how well young disabled people will manage direct payments.
- f** One of the main ways in which young disabled people might use direct payments is to purchase personal assistance. This raises issues about how the relationship between young disabled people and their personal assistants would be managed.

Background

A 'direct payment' is money given to people assessed as requiring certain kinds of support. It is paid by Social Services Departments. Direct Payments have been taken up by disabled adults as a way of buying individualised support services. Typically they have been used to get support at home and/or to pay for a support worker (often called a personal assistant).

The Carers and Disabled Children Act 2000 extended access to direct payments to 16- and 17-year-old disabled young people from April 2001.

More detailed information about how direct payments work can be found elsewhere – for

example, at www.ncil.org.uk (the website of the National Centre for Independent Living) and www.viauk.org (the website of Values Into Action). Box 1 gives examples of existing initiatives in this area.

For young disabled people, direct payments are a new way to access more independent living and pursue lives with the same opportunities as their non-disabled peers. But they raise some potentially problematic issues, for example:

- how to promote direct payments to young disabled people;

Box 1: Existing initiatives

The first part of the project involved finding out what other organisations were doing in relation to the extension of direct payments to 16- and 17-year-olds. The following groups and individuals are examples of relevant initiatives around direct payments and personal assistance specifically for young disabled people.

- **Norwich Social Services**

In an attempt to develop direct payments for parents of disabled children and disabled young people a Norwich Social Services project consulted with 16- to 19-year-olds. The young people talked about their desire to have access to the full range of social and educational opportunities as their non-disabled peers and were enthusiastic about the opportunities created by direct payments.

To find out more: contact Sue Norgrove, Development Officer, Children with Disabilities Team, Social Services Dept., 31 Norwich Street, Dereham, Norfolk NR19 1DH, tel: 01362 694711, email: sue.norgrove.socs@norfolk.gov.uk.

- **West of England Centre for Inclusive Living (WECIL)**

WECIL have been running a Personal Assistant Support Scheme for young disabled people. The project - 'Youth PASS' - aimed to enable young disabled people to gain experience of using personal assistance in a one-to-one relationship which is under their control and direction. PAs were recruited, trained and supervised by Youth PASS staff to carry out activities of the young person's choosing both inside and outside the home. A video and Good Practice Guide for providing personal assistance to young disabled people are available from WECIL.

To find out more: contact Youth PASS, WECIL, Leinster Avenue, Bristol, BS4 1AR, tel./minicom: 0117 903 8900, email reception@wecil-ltd.demon.co.uk.

- **Swindon People First**

Swindon People First have been researching issues about direct payments for people with learning difficulties of all ages and have produced an accessible, illustrated pack about direct payments and what it means to employ a personal assistant.

To find out more: *Journey to independence: How to run your life with direct payments* is published by the British Institute for Learning Disabilities (price £25 plus £2.50 p&p) and is available from Plymbridge Distributors, tel: 01752 202301 or email orders@plymbridge.com.

- **Essex County Council Social Services Department**

The Department has produced a short guide to Direct Payments for 16- and 17-year-old disabled people.

To find out more: The guide is available free in a number of formats from tel: 01245 434134; fax: 01245 268580; textphone: 01245 434090.

- **Greater Manchester Coalition of Disabled People: Young Disabled People's Forum**

The Forum has been involved in producing an independent living skills manual and video, *Moving on: A training manual for young disabled people*, which is also available in Braille, audio tape and large print formats. Whilst not explicitly about direct payments it is a helpful resource in the area of independent living for young disabled people.

To find out more: about the Young Disabled People's Forum or about Independent Living and Disability Equality, tel: 0161 273 8141 or email gmcdp@globalnet.co.uk.

- **Empower 2001**

Empower 2001 is a London-based organisation of young disabled and non-disabled people who run training weekends for young people interested in learning more about using personal assistants or being a personal assistant.

To find out more: email hq@empower2001.org.uk or look at the website www.empower2001.org.uk.

- how to support young disabled people to access direct payments and to manage a personal assistant (PA), if they choose to have one;
- how to deal with the administrative, financial and legal responsibilities of being a direct payments recipient;
- how to respond to questions or concerns that parents of young disabled people might have.

Supporting young disabled people to manage a direct payment

Being a direct payment recipient involves a number of responsibilities. A PA naturally acquires the rights of an employee and there have been concerns about the legality of a 16-/17-year-old taking on the contractual and statutory responsibilities of an employer. However, as with some people with learning difficulties, a young person need not assume responsibility for these matters but instead can arrange for an independent living scheme, for example, to organise this for them. NCIL have said that one insurance company has agreed to underwrite Employers Liability Insurance for 16-/17-year-old young adults (who are in receipt of direct payments and who register as employers).

The views of young disabled people

As part of the project, David Abbott, from the Norah Fry Research Centre, University of Bristol, and April Bird, a freelance researcher, organised a group of young disabled people to meet to produce a resource about direct payments for young disabled people (see Box 2).

Fifteen young disabled people and PAs came together from across England to meet in London over two Saturdays. Only two members of the group were in receipt of direct payments. Several others were in the process of applying; they had been finding this difficult as there had been many delays and obstacles.

The group felt that the following messages and themes were the key ones which needed to be communicated in order to promote direct payments to young disabled people:

- Direct payments can be a good way of achieving more independence, choice, freedom and control. They can be instrumental in providing an important alternative to residential options.
- Direct payments can change your relationship with your parents – make you less reliant on them and even have a better relationship with them. It doesn't mean however that you have to leave home – unless you want to.
- Direct payments aren't necessarily easy to get and there are anxieties about the process of applying. The group had concerns about needs assessment and whether their own views on what their needs

Box 2: Getting information to young disabled people about direct payments

The group of young people involved with the project decided to create a magazine with an audio version on CD aimed at young disabled people, with a range of styles and formatting and quite a lot of personal experiences, views and stories. They wanted to get the balance right between saying how good they thought direct payments could be and the difficulties that young disabled people might face in actually accessing them.

In order to produce the material for the magazine the young people used disposable cameras to take pictures of their lives – things they liked doing with other people, with their PAs, and the kinds of assistance that their PAs routinely gave them. Group members wrote about their own experiences and interviewed each other to find out more. They were keen to include a problem page and also sources of advice, support and information.

The result of this work is a one-off magazine called, *'Living it Up!'*. For details of how to get hold of this and the CD that accompanies it see 'How to get further information'.

were would be taken seriously. They were also worried that social services departments wouldn't know about it or wouldn't adopt a helpful attitude towards a young disabled person enquiring about direct payments.

- Given the potential barriers it was thought to be crucial to stress that young people would not be alone with the decisions and responsibilities relating to applying for and getting a direct payment. Sources of information, advice and support are really important. Young disabled people could talk to other young people who have already got direct payments or they could talk to older disabled people who could give mentoring support.
- Having a personal assistant could be life-changing in all kinds of ways. It was seen as a quite unique kind of relationship, characterised by gains in independence and especially getting access to a better social life. However, the relationships could be stressful and intense and it could also be very hard to find PAs, especially the 'right' PAs. Common problems were that it was difficult to find and 'vet' PAs; that PAs could come and go from the life of a disabled young person; that it took a long time to train them well; that the boundaries between employer and friend could sometimes be confusing. One young disabled, Muslim man said that it was hard to find a PA who was sensitive to his religious and cultural practice.

The views of parents

It is very likely that a young person will need the active support of their parent or carer in order to access a direct payment successfully. Parents may need to be assured that direct payments do not automatically mean that their son or daughter will want to leave home but may be used to support them at home and/or at college.

The views of the Project Advisory Group

The project was supported by a Project Advisory Group of parents and professionals from local authorities, Connexions, Government and organisations of and for disabled people. The group acknowledged the difficulties that young disabled people could face in accessing direct payments and the concerns that parents and professionals might have about the responsibilities inherent in being a direct payments recipient. Issues of safety and welfare were raised in relation to the PA/user relationship. However, the group recommended that the resource for young disabled people (see Box 2) should primarily focus on what was potentially positive about direct payments without ignoring the possible barriers. What was missing was a resource which promoted the idea behind direct payments.

Advisory Group members were aware that low levels of take-up of direct payments for young disabled people might be due to the scepticism of some local authorities. Some of the issues faced by young disabled people were similar to those faced by adults with learning difficulties. This group also had to work hard to persuade local authorities that they could be effective recipients of direct payments as long as proper support mechanisms were in place.

The Advisory Group also reflected on the particular issues that would face minority groups within the population of young disabled people. Would young people from black and minority ethnic backgrounds find PAs with a similar background or sufficient insight and sensitivity to any needs or requirements specific to their cultural background? Similarly, would young disabled gay, lesbians and bisexuals be able to find PAs who were also gay or who would feel comfortable with the sexuality of the young disabled person?

About the project

This work was co-ordinated by David Abbott at the Norah Fry Research Centre, University of Bristol, with help from April Bird (work with young disabled people), Jan Alcoe (design and layout of *Living it*

Up!) and Icon-Tact, Bristol (CD). The project was also supported by a Project Advisory Group of parents and professionals from local authorities, Connexions, Government and organisations of and for disabled people.

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How to get further information

'Living it Up!' is available free of charge while stocks last as a printed magazine and a CD from the Norah Fry Research Centre at 3 Priory Road, Bristol BS8 1TX, Tel: 0117 923 8137, minicom: 0117 928 8856, Fax: 0117 946 6553. The magazine will also appear on the Norah Fry website:

www.bris.ac.uk/Depts/NorahFry/.

You can contact David Abbott at the Norah Fry Research Centre at the address above and by email: d.abbott@bristol.ac.uk.