



SCOTTISH AUTISM SERVICE NETWORK

## **Direct Payments and How They Can Help People with Autistic Spectrum Disorders and Their Families**

The Community Care (Direct Payments) Act was published in 1996 and in 2001 the Scottish Executive set up and funded Direct Payments Scotland to increase the uptake of Direct Payments throughout Scotland.

### **What are Direct Payments (DP's)?**

A cash payment made by the Social Work Department to an individual instead of the department providing a direct service (such as attending a respite facility or day centre). It is money for support that people have been assessed as needing in their Community Care Assessment (CCA). A DP means that the recipient is in control of what is provided, how and by whom. A DP is not extra help, it is an alternative to services in the form of a cash payment so that the person can have more control over the support they receive. The Direct Payments scheme focuses on independent and user led support and aims to increase the choice, control and flexibility that the disabled person them self (or parent, if the person is under 16 years old) has over the way they live and access assistance for their needs.

### **Who can access Direct Payments?**

People with a disability over the age of 16, with learning difficulties, mental health difficulties, and physical impairments. Also older people with support needs and people with long term illnesses (such as arthritis or cancer) can utilise DP's. Parents of children with disabilities can receive DP's to purchase the services their children are assessed as needing.

DP's can't be offered to people who are restricted by mental health (e.g. patients detained under mental health legislation). People who gain DP's must be "willing and able" to manage them, with assistance if necessary. Others may assist the person but they must remain in charge of arrangements and are accountable for how the money is used. Social Work decides if a person is "willing and able" to manage a DP.

### **How can I get a Direct Payment?**

Anyone who has been assessed as needing support in their Community Care Assessment (CCA) as requiring at least £200 per week worth of support should be able to access a DP. If you have already had an assessment, you may be reassessed before a direct payment could be paid to you. The first step in getting a DP is to get a Care Manager/Social Worker for the individual through Social Work. An individual may also need, or benefit from, a representative to help put their DP into place. It is important to be clear about what and how much support you think the person needs and when you need it before you have your CCA.

### **What are the responsibilities for local authorities to provide Direct Payments?**

It has been mandatory for all local authorities to offer DP's since June 2003 and they have a responsibility to inform people of them. However, they also need to be sure the recipient understands the process and implications fully before they go ahead with it. Ideally the individual should be told about DP's before they have a CCA. This means they would have an opportunity to talk to a support organisation and do a self assessment before they are formally assessed by Social Work. This will give them a clearer idea of what they should expect from Social Work and what needs they should highlight in the assessment. Social Workers can say that they feel someone isn't appropriate for receiving a DP, but they would have to have a clear case. For instance, if Social Work feels the extent of cost outweighs the benefit, they can decide not to grant a DP to an individual, although the person can appeal against this.

### **How long will the process take?**

There is no set time frame. It totally depends upon how advanced the DP system in your local authority is, how quickly you can access a Social Work Assessment and whether you choose to use a support organisation or not.

### **What can Direct Payments be used for?**

For whatever support is needed for independent living and for practical assistance, for example; personal care, support during day to day activities (such as shopping, cleaning and cooking), accessing social activities, support at work or in finding a job, support with education activities (could be used for scribes etc), support to go on holiday, respite care (at home or elsewhere), and equipment.

To access this support, the DP can be used to employ a Personal Assistant or Support Worker, buy support from an agency (such as a nursing or care agency) or buy services from the local authority or a private provider.

DP's do *not* cover costs that individuals/families do not normally receive from the Social Work Department such as childminding, money for clothing, employment supplements etc. DP's can also not be used for education services for children as these are provided by the Education Department. Also DP's are meant to assist independent and community living; therefore you can't use them to pay for permanent residential accommodation.

### **What are the advantages of Direct Payments?**

Many people find that they have difficulty accessing Social Work support, that the appropriate support doesn't exist, that support that is provided may not be fully suitable for their needs, or that staffing is inconsistent. For instance, a person may find that the Support Worker supplied by Social Work cannot come at times that suit them or that a number of different people may be used. With a DP you can arrange for them to come at whatever time you want and use specific staff that you choose, to ensure continuity. Also, you may be able to utilise respite in your own home, at a place you choose or to take a break, rather than at a statutory service chosen by the local authority. A big advantage, especially for adults with ASD is that DP's can be used to enable independent living and access to the community.

DP's give you greater freedom as a major factor is that you can decide who will best meet your needs, and when. You may also have more flexibility if you need a greater amount of support at particular times.

### **What are the disadvantages of Direct Payments?**

Using DP's involves a large amount of management and responsibility on the part of the individual or their carer/representative. For instance; arranging support and staffing, handling problems, keeping relevant paperwork, and employer responsibilities. It can also be extremely difficult to find trained staff to employ, especially who have experience and understanding of ASD's. However Direct Payments recipients can receive support to manage these issues from local Direct Payments support organisations, advocates, circles of support, independent living trusts etc. Also, some people have experienced difficulty in gaining DP's from their local authority.

### **How much money will I get?**

This will depend on what your CCA states and what your individual needs are. The Community Care Act (Direct Payment's) 1996 states that the amount you receive must be enough to buy the support you've been assessed for in you CCA. Each local authority decides its' own rates and will calculate this based on how much it costs to employ someone to do the specific role on an hourly rate, with an amount added for additional costs such as insurance, tax, the cost of advertising and interviewing applicants, administration costs, holiday pay, sick pay etc.

### **Will I be classed as an employer and what legal responsibilities would I have?**

Managing DP's is a huge responsibility but you can get help with managing them. Support organisations can provide training and information on being an employer and certain publications (available from support organisations) can provide advice. Also, Social Work will want to be sure that your needs are being met and that you are keeping to the agreement; therefore your DP arrangements will be reviewed regularly.

### **Would the direct payment include extra costs, such as liability insurance, health and safety equipment, training for staff etc?**

Yes, a percentage is allowed for these factors. However what exactly is included and specific amounts will differ amongst different local authorities. You should look into all the possible costs (this information can be gained from some of the organisations detailed at the end of the article) and discuss what will be added to your basic DP for these with your Social Worker before making a final decision on whether to use DP's.

### **Will Direct Payments affect my other benefits such as DLA?**

No, they do not affect any benefits such as DLA, Attendance Allowance, and Incapacity Benefit. Also, a DP does not affect ILF payments, it will compliment it. You will not be taxed on DP's and it will not affect any employment or social security benefits that you receive. You don't have to be receiving DLA or any specific benefit to access DP's, however; DP's must be paid into a separate bank account from your normal account.

### **Are Direct Payments means tested and will I need to contribute in any way?**

You may need to make a contribution and charges are means tested from eligible income, but this also happens with direct services from Social Work. The local authority will charge you in the same way it charges people who use direct services.

### **Can I still access Social Work services whilst using Direct Payments?**

You can have part or all DP's therefore you can have mix of DP's and direct services provided by Social Work if this suits your needs. For instance; you might choose to continue using one week of your annual residential respite quota, but use the money that would pay for the other 2 weeks as a DP to organise a Support Worker to come into your home for a certain amount of hours per month. Alternatively, you might decide to organise all of your own support with DP's.

### **Can I employ a family member as a Personal Assistant/Support Worker?**

You currently cannot employ a close relative living in the same household. However, you can employ from members of your family in exceptional circumstances if they live in a different home. The local authority has discretion to allow this in exceptional circumstances and each case would be viewed individually.

### **How Personal Assistants/Support Workers are police checked?**

Criminal record checks (called 'Disclosures') are available, and will enable you to find out whether the people you offer employment to as a Personal Assistant have a criminal record or not. You will be able to request an enhanced disclosure from Disclosure Scotland which may be arranged by your local authority or support organisation or if you are acting as the employer you can arrange this yourself for a small fee.

### **If I am able to work, can I access Direct Payments?**

Yes. Many people who have additional or care needs work, but may require assistance in certain areas. If a CCA identifies support needs you can still work and claim DP's. This may be for support at home with certain tasks, with accessing social and community activities outside of work, or even for support within the workplace via a Support Worker if this is assessed as a need.

### **As Direct Payments focus on choice of individuals and being user led, how would I ensure my child's choices are accounted for as he is non verbal?**

The Children Act 1995 states that every child has the right to be treated as an individual and to form and express views on matters affecting them. Therefore it is important that their views are sought. A balance needs to be reached in listening to and understanding what children want and with ensuring their needs are met. Children in Scotland are producing a good practice guide on consulting with disabled children and young people regarding their needs.

### **Who can I gain independent advice and support from about Direct Payments?**

Your local authority, local support organisation, UPDATE or SPAEN (Scottish Personal Assistant Employers Network) can provide information and advice. Many people who consider using DP's are worried about employing staff and managing the financial

aspects, but support organisations can give information, advice and direct support regarding meeting your care and support needs and also how to manage the DP money.

The National Centre for Independent Living (NCIL) also provides information, advocacy, peer support, guidance, training for employers, training for Personal Assistants, a recruitment Service, an emergency back-up service, and a payroll service called 'Payroll Solutions' to people who want to use DP's. They have a website which contains useful information, examples of employer contracts, job descriptions, application forms, and useful publications and have produced a very useful 'Employers Toolkit' to assist people using DP's to employ Personal Assistants. Also, the Scottish Personal Assistants Employers Network (SPAEN) provides a forum for people employing Personal Assistants to discuss and share experiences and issues and gain information.

If there isn't a support organisation in your local authority you should ask your Social Worker if they can put you in touch with a local support group for people who receive DP's, or with a local advocacy or other organisation that has experience of this. You can also ask for help and advice from a friend or relative (see 'Circle of Support' below).

### **What is a Support Organisation?**

When Direct Payments Scotland was set up, part of its role was to develop local support organisations, who are user led independent organisations that offer support, information and services to people considering and receiving DP's. However, the organisation Direct Payments Scotland is now no longer in existence, but there are support organisations providing this service in various regions across Scotland. The support they provide may vary, but generally it will consist of services, information, advice and advocacy, and regarding DP's. This could include; training for Personal Assistants and Support Workers, assistance in recruiting staff, guidance on employer legislation and a payroll service. The Support Organisation should also provide training on issues such as: recruiting and interviewing, day to day management of staff, employment law, insurance, tax and national insurance, statutory sick pay, budgeting and how to manage financial requirements, training, child protection and police checks, health and safety etc.

### **What is a 'Circle of Support'?**

Sometimes an individual requiring services may need assistance in planning and implementing for their needs and life choices. A good way to address this can be to develop a 'Circle of Support' which is a group of people who assist and enable the individual in creating and implementing a 'life plan'. This revolves around the individual and is developed specifically to meet their needs, preferences and choices. The people involved work together on the individuals' behalf to explore suitable opportunities, care provision, support, aims, goals and desires, and will ensure they will take account of the person's wishes. The individual still has a say in how their needs are met, but do not have day to day management responsibilities over Personal Assistants/Support Workers or the DP money.

The Adults with Incapacity Act (Scotland) 2000, states that the experience of using support services should be positive and that because a person may not be able to control or manage some aspects of their support (such as financial or employer responsibilities), it

does not mean that cannot exercise choice and control over other aspects of their support and life. It acknowledges that people may use different languages or methods of communication and encourages preventing this becoming a barrier to the person having a say in their life and support decisions.

'Circles of Support' are often made up of family members, carers and friends, but the individual needs to consent to them managing their affairs on their behalf. People with more complex needs can set up an 'Independent Living Trust' where a group of interested person's manage the individuals needs and wishes, but a named person has legal responsibilities as the DP employer on behalf of the individual.

### **Can anyone help me manage the financial aspects of using Direct Payments?**

Local authorities carry out financial monitoring of payments which take place every 4 weeks or every quarter and you will also receive regular statements. There will also be a more in depth financial audit of payments which should happen every 3 to 5 years.

Many individuals want the independence and control over the services they receive that come with using DP's, but not burden of financial management. Therefore certain organisations offer payroll services. Most support organisations have these and they will take care of your employees pay, national insurance, tax, payslips etc for a fee. NCIL and the Council for Voluntary Service may also offer payroll facilities. Alternatively, you can also choose to pay for payroll support from an accountant or book-keeper.

### **Are Direct Payments the same in Scotland as the rest of the UK?**

No, there are differences in the different nations. The main differences are that in England DP recipients can employ close relatives who live in different households, in exceptional circumstances they can employ close relatives in the same household, carers can get Direct Payments in their own right, can't buy local authority services in England, and can't pay Direct Payments to an attorney or guardian. There also appear to be differences in the focus of who is in priority for receiving DP's

### **What happens if I don't want to use Direct Payments?**

Nobody is obliged to take a direct payment. You may be asked if you want to use DP's or told about them, but you do not have to take them up.

### **If using Direct Payments does not work out for me, can I go back to receiving direct services from Social Work?**

Yes, but you should contact your Social Worker as soon as possible and ask for your needs to be reassessed. If your needs are not being met, the local authority will have a responsibility to assist and provide support. This might mean that you are given more assistance in carrying on using DP's or that your CCA recommendations are changed, so that the level of support, or how it is delivered, are altered. However, you can ask for DP's to be stopped and in doing so the Social Worker would need to arrange services as an alternative.

## Conclusion

### How could people with ASD and their families benefit from DP's?

People may use DP's in many different ways, which is one of the advantages. This means that people with ASD are not receiving prescribed services that are perhaps not fully suitable for their needs or may have been developed with people with learning disabilities in mind rather than ASD.

Although the many characteristics of ASD are the same for everyone, the condition affects individuals and their families in different ways, and using a DP means that the person or their parent/carer can tailor the support to their specific needs. There are disadvantages to DP's in the amount of self management needed, the employer status that goes with the role, and dealing with finance. However, if a person is confident in their management skills, has friends and family who can help, or is willing to use a support service, DP's can have benefits.

Many people who are currently receiving direct services from Social Work find that these may not be entirely suitable for them/their child with ASD. For instance, many parents comment that Support Workers often change and this can cause problems with consistency for their child. Also, some existing day provisions, playschemes, respite centres and employment schemes etc that are currently used by Social Work may provide a good service generally, but perhaps don't meet the very specific needs of individuals with ASD (for example, the environment may cause the person difficulties due to sensory sensitivity, or the staff may not be fully trained in the need for structure and routine for people with ASD). There are cases where a person has been assessed as having certain needs, but has not been able to access a direct service through the normal system, as no such service exists. DP's could mean that some of these issues can be addressed and people may be able to access support that suits their needs more effectively. Some examples of how a person with ASD or their parent might use a DP are outlined as follows;

- An adult with ASD may require support in the home and can use DP's to pay a home help rather than relying on social work or housing services.
- Rather than attending a day service, a person with Asperger's syndrome may wish to use the DP for a worker to help them access local community social activities.
- Rather than their child attending a holiday playscheme for children with general disabilities, a parent could pool their DP's together with other local parents to pay for an ASD specific playscheme that suits their needs better.
- A person with ASD may have a Support Worker supplied by Social Work who assists them for 10 hours per week, but they don't always come at the times that suit them and a number of different workers may be used. They could use their DP to pay for a Support Worker that they choose and who supports them when they specify.
- A parent of a child with ASD might be offered two weeks respite annually, to be taken in one week blocks. However, this causes their child stress due to the change in environment and thus more work for the parent when they return home. The parent may feel that shorter, more regular breaks would be more beneficial. They could use

their DP to pay a trained Support Worker to take their child out twice a month so that they can have a break and spend more time with their other children.

- An adult with ASD may be able to access and pay for an employment support service using their DP to assist them into work if this is assessed as a need

The main idea behind Direct Payments is that people with disabilities will have more choice, control and flexibility over the support they receive. Whether they will work for you is also a matter of choice, but it is an alternative option to standard services that may have been offered in the past.

### **Useful Contacts**

#### **Update** (Scotland's National Disability Information Service)

27 Beaverhall Road

Edinburgh, EH7 4JE

Tel: 0131 558 5201

E-Mail: [info@update.org.uk](mailto:info@update.org.uk)

Website: [www.update.org.uk](http://www.update.org.uk)

#### **SPAEN** (Scottish Personal Assistants Employers Network)

Unit 9, Motherwell Business Centre,

130 Coursington Road

Motherwell, ML1 4LW

Telephone: 01698 250280

E-mail: [info@spaen.co.uk](mailto:info@spaen.co.uk)

Website: [www.spaen.co.uk](http://www.spaen.co.uk)

#### **Glasgow Centre for Inclusive Living**

117-127 Brook Street

Bridgeton

Glasgow, G40 3AP

Telephone: 0141 550 4455; Fax: 0141 550 4838; Minicom: 0141 554 6482

Website: <http://www.gcil.org.uk/>

For the Scottish Executive Guide to Receiving Direct Payments in Scotland visit

<http://www.scotland.gov.uk/Publications/2002/04/14662/4093>

The Scottish Consortium for Learning Disabilities (SCLD) provides an Easy Guide to Direct Payments in Scotland. You can access this on their website at:

<http://www.sclld.org.uk/pdf.pl?file=SCLD%20payment%20guide%20web.pdf>

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