Direct Payments- A brief guide for parents and carers of children with autism spectrum disorders

Introduction

‘A Direct Payment Scheme is a means to an end, and the end is Independent Living’ John Evans (2000)

There are two types of direct payments: those concerned with benefits being paid directly into a bank account, and direct payments given to individuals instead of receiving direct services from the local authority. This information sheet is concerned with the latter and will provide a brief guide to direct payments including information on how to apply for them.

This information sheet is relevant to people living in the whole of the UK but please note that the direct payments schemes may vary slightly depending on the country where you live. The information sheet will outline the relevant legislation for England, Scotland, Wales and Northern Ireland but this is intended as guidance only and is not a statement of law. It is always advisable to get further information from a local source to ensure you are fully aware of the relevant guidance and legislation and how this affects you.

The term local authority ‘LA’ will be used throughout this information sheet where the information is relevant to all of the UK. LA will be used to mean the local authority social services (England), local council (Wales), local authority social work department (Scotland) and local authority health and social services trust (Northern Ireland).

What are direct payments?

Direct payments were introduced to provide more flexibility for those who have been assessed as being in need of services. A person receiving direct payments can arrange their own services instead of receiving the services directly from the LA. The idea is that direct payments provide a person with more freedom and
control over the community care services that they receive and for some, this can lead to greater independence.

**Who can receive direct payments?**

The following provides details of the client group who may be eligible for direct payments—

- Disabled people aged 16 and over (this group includes older people, disabled adults and disabled young people aged 16 or 17)
- A person with parental responsibility for a disabled child (under the age of 18) or disabled person with parental responsibility for a child (this group may include a parent or others, such as a grandparent who has parental responsibility)
- Carers aged 16 and over (Direct payments could be given to unpaid carers in respect of their own needs but not for services in respect of the needs of the person they care for.)

(Clements, 2006)

**What does this mean for parents of children with an autistic spectrum disorder (ASD)?**

Direct payments may be a suitable option for some families. Many families of children with an ASD feel that the services they are offered from the LA do not entirely meet the needs of their child. In areas where there are limited services, direct payments may be an option to create more choice. However, the payments must be to pay for the services that a child has been assessed as being in need of.

The following are some examples of how direct payments could be used:

- To pay a personal assistant to support your child when the family is, for example, going swimming or involved in another activity; (if you have other children this could mean spending more time as a family without the worry of solely supervising your child with an ASD).
- If your child has been assessed as needing respite, then direct payments could give you more flexibility as to who provides the respite care and when.
- If your child has been assessed as needing support in the home then direct payments could provide you with the opportunity to employ a personal assistant at the times of the day when the support is needed most (for example, getting ready for school).
- Relaxation therapy or driving lessons may be a creative way in which direct payments can be used for carers.

This scheme will not be right for every family but it is worth considering. You need to be fully aware of the implications of receiving direct payments in terms of becoming an employer and the responsibility that this brings. This will be discussed further on and will explain the support that you can get with choosing this.
How to access direct payments

The following is a simple chart to show you the process;

1. Are you getting any support from social services?

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2. You will need to contact your LA and request an assessment of your child’s needs (contact the Autism Helpline for an information sheet titled ‘Caring for a child with an ASD– getting help from social services.’)

If yes, go to step 4, if no go to next step

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3. If a social worker has carried out an assessment they will then decide whether your child is in need of services and whether your child’s presenting needs meets the LA eligibility criteria.

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4. If your child meets the eligibility criteria, then there needs to be agreement on the services provided to meet the assessed needs.

A care plan will then be drawn up

If you already receive support from social services you should have a care plan already. You can request a copy of the care plan from the LA.

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5. The social worker should now offer you the choice between direct payments or receiving services (as long as it is in your child’s best interest and you meet the criteria to receive direct payments). If not offered to you, then do ask about your choices.

If you already are receiving services then you can discuss the option of direct payments with your social worker

Your decision

Direct Services
LA to provide services specified in care plan.

Mixed Package
Sometimes this may be suitable where you would receive part direct payment and part services from the LA.

Direct Payments
The amount and the arrangements are discussed and agreed upon and the monies are then paid to you to arrange your own services specified in care plan.
This process all seems quite straightforward but in reality it is not always this easy and you may come up against some obstacles. A common issue we hear about on the Autism Helpline is that the needs of children with an ASD and the impact on the family are not always recognised and assessed thoroughly by the LA. It is important for you, if told your child does not meet the LA eligibility criteria, to ask them for a copy of their criteria. Refer to the ‘caring for a child’ information sheet for details about complaints procedures if you are not happy with your assessment.

Direct payments for carers
Social services have the ‘power’ to provide services for carers following a carer’s assessment and social services can provide direct payments instead of providing them with a service. Please note as mentioned previously, direct payments could be given to carers in respect of their own needs but not for services in respect of the needs of the person they care for. For example, respite care is considered to be a service for the child’s need rather than the carer and so this would be assessed in the child’s assessment rather than the carer’s assessment. However, the provision of services is discretionary: social services have the ‘power’ to provide them but not an actual duty to do so. Nevertheless, this does not mean that local authorities can ignore carers’ needs and they cannot set blanket policies about who they are providing services for. LAs must make decisions by assessing each carer’s circumstance, individually.

Are direct payments available for all families who have a child with an ASD?
Direct payments should be an option for all families but there are considerations that LA will take into account, following relevant regulations, to see if a person is entitled to direct payments. The main entitlements are dictated below:

1. Direct payments must relate to the user’s assessment of need (The relevant children’s assessment or carer’s assessment)
2. Users must be willing to receive direct payments (ie it has to be your choice and you shouldn’t be forced into receiving direct payments)
3. Users must be able to manage the payments (alone or with assistance)
4. Some people may be excluded from receiving direct payments if subject to certain mental health or criminal justice legislation. (For more details on eligibility restrictions see the following website– http://www.everychildmatters.gov.uk/_files/D1679F3952A76FCC32BA4EC99E76FD65.pdf)
5. There are restrictions on who can provide the services. Regulations do state that you cannot use direct payments to pay a close relative who lives in the same household unless the LA is ‘satisfied that securing the service from such a person is necessary for promoting the welfare of the child in need’.
6. There are some services that cannot be paid for by using direct payments. For example, direct payments cannot be used to pay for children’s residential accommodation for any single period in excess of four weeks, and for more than 120 days in any period of twelve months.
7. The amount paid for the direct payment must be equal to their estimate of the reasonable cost of the service to meet the assessed need. There must also be payments to help meet the cost of you becoming an employer (for example, start up costs, national insurance, and sick pay).
8. When choosing direct payments, you will become the employer and therefore you need to be aware of the obligations that come with this. You will be obliged to ensure that the direct payment is used to pay for services to meet the assessed need. This will be monitored by the LA. The LA has the power to seek repayment if it is felt that the payments have not been used to meet assessed needs.

(Disability Alliance, 2005, and Clements 2006)
Financial contribution

People receiving services from the LA are sometimes required to contribute to the cost of care. As with receiving services you may be required to contribute towards the cost of the care purchased with direct payments. These charges will be means tested. The LA should only assess your income once they have decided which services to offer, so your ability to pay should not influence their decisions about what your child needs.

If you feel the charges are unreasonable or that it is not possible for you to pay them, then you should find out first how the charges were worked out. Each LA has a policy on charging for services. You should then seek specialist advice from one of the helplines listed at the end of this factsheet. It may be advised to appeal against the amount of direct payment offered to you, following the LA appeals process (details should be available from the LA on how to appeal and who to appeal to.)

Support with receiving direct payments

The LA should ensure that you have access to the advice, support and training that you require to receive direct payments. LAs should have a Direct Payment Support Service to help those using direct payments with recruiting, payroll and other help needed with setting up and running a direct payment scheme. You will be given a start-up fund which will help cover the cost of administration and recruiting and you should receive a part payment to help with on-going administration costs. For some families who decide that they need support with being an employer, it may be possible for them to use some of this fund to pay the support service who can take on some of this role for you (such as payroll). This may ease some of the pressure of becoming an employer.

The National Centre for Independent Living has useful information on their website about being an employer, including information on payroll, recruiting and health and safety checks. On the website there is also a link to find out where your local Direct Payment support scheme is located–http://www.ncil.org.uk/employers_kit.asp

The amount of support provided by the local support schemes varies so it is best to contact them directly to discuss your individual situation.

If you are a parent of 16/17 year old and considering direct payments, then it may be useful for your child to have access to advocacy support. Please see the advocacy contacts towards the end of this information sheet to find a local advocate.

Will the direct payments be reviewed and what if after receiving direct payments, I decide they are not right for my child?

A review should take place within six weeks of a family receiving a direct payment but if you feel you need an early review then do request one. The LA needs to satisfy itself that the individual’s needs are being met by the services that they receive The LA should ensure that the direct payment is being used for the services that the individual has been assessed of needing (ie relating to the care plan). Whilst in the initial stages of having direct payments, you may find that reviews are more frequent to ensure that all is satisfactory.

If at any point you are not happy with direct payments and the way this is working for your child, then you should speak to your social worker or the person in charge of direct payments in your LA. It is your choice whether to continue with direct payments and if you decide to stop having the payments then the LA should provide the services instead.

There may be some circumstances where the LA decides to discontinue the payments. This may happen for example, if they feel your child’s needs (as stated on care plan) are not being met by the services you are paying for with the direct payments. Your local authority should inform you if they are planning to stop the payments.
If a child’s or carer’s needs change and this affects the support needed, then the LA may reassess that person’s needs and this may affect the amount of direct payments provided. The LA should not withdraw the payments if they feel the person’s needs have changed without having reassessed their needs. If you feel that your child’s needs or your needs as a carer have changed then contact the LA as soon as possible and discuss how this affects the level of care and support needed.

Conclusion

Direct payments may sound a suitable option for you and your child and you may like the idea of having more control over the services you receive from the local authority. For other families the idea of becoming an employer and having this extra responsibility may seem rather daunting. Direct payments will not be right for every family but if you do opt for this, then it is important that you have access to a good support scheme and that you are fully supported by your local authority in getting this support. There is growing literature written about direct payments that provides help for becoming an employer and help with setting up a direct payment scheme. Having spoken to families directly it would seem that the way direct payments are set up varies across local authorities. It is important for families to have this choice between receiving services or payments and it is hoped that for many families, the payments will lead to getting services that fully support their child’s needs.

For further information and support with direct payments, please see the following references and contacts.

Further Contacts

**Carers UK** is a nationwide organisation and has a wealth of information on their website regarding support for carers, including the Carer’s Assessment.

Carers UK  
20-25 Glasshouse Yard  
T. 020 7490 8818  
F. 020 7490 8824  
info@carersuk.org  
[www.carersuk.org](http://www.carersuk.org)

CarersLine T. 0808 808 7777  
*Wednesday and Thursday  
10am-12pm and 2pm-4pm*

Carers Scotland  
91 Mitchell Street  
Glasgow G1 3LN  
T. 0141 221 9141  
info@carerscotland.org  
[www.carerscotland.org](http://www.carerscotland.org)

Carers Wales  
River House  
Ynsbridge Court  
Gwaelod-y-Garth  
Cardiff CF15 9SS  
T. 029 2081 1370  
info@carerswales.org.uk  
[www.carerswales.org](http://www.carerswales.org)

Carers Northern Ireland  
58 Howard Street  
Belfast BT1 6PJ  
T. 028 9043 9843
National Centre for Independent Living (NCIL) provides information on direct payments and details of local support schemes who offer support with managing direct payments. They also have information about becoming an employer.

NCIL
4th Floor, Hampton House
20 Albert Embankment London
SE1 7TJ

Tel: 0207 587 1663
Fax: 0207 582 2469
Text: 0207 587 1177
E-mail: info@ncil.org.uk

Legal contacts

The Disability Law Service provide legal advice on community care law (England and Wales only)
Tel: 020 7791 9800
Fax: 020 7791 9802
E-mail: advice@dls.org.uk
Opening hours: Monday to Friday 10:30am – 1pm and 2 – 4pm

The Children’s Law Centre provides legal information for members of the organisation regarding all aspects of law affecting children in Northern Ireland.
http://www.childrenslawcentre.org/
Tel: 028 90 245704

The Scottish Child Law Centre provides information and advice for parents and young people regarding the law affecting children in Scotland.
54 East Crosscauseway
Edinburgh
EH8 9HD
Information Helpline Tel: 0131 667 6333
enquiries@sclc.org.uk

Advocacy Contacts

The following contacts have directories of local advocacy services-

Action For Advocacy (A4A)
PO Box 31856, Lorrimore Square, London SE17 3XR
Tel. 020 7820 7868
www.actionforadvocacy.org.uk

Advocacy Resource Exchange
162 Lee Valley Technopark, Ashley Road, London N17 9LN
http://www.advocacyresource.net/

BILD (British Institute of Learning Disabilities)
Campion House, Green Street, Kidderminster, Worcestershire DY10 1JL
Tel. 01562 723027, web: www.bild.org.uk

Scottish Independent Advocacy Alliance (SIAA)
References and further reading


Scope (2004). *In the driving seat- Direct payments for your child.* London

(http://www.scope.org.uk/issues/directpayments/index.shtml)

The Department of Health publish a direct payment guide for parents and this available from their website-

http://www.everychildmatters.gov.uk/socialcare/disabledchildren/directpaymentfaqs/)

or contact:
Department of Health Publications
PO Box 777
London
SE1 6XH
Tel: 08701 555 455
Fax: 01623 724 524
Quoting 31213/A Parent’s Guide to direct Payments to order a copy

Other websites

Dial UK is a national organisation for a network of approximately 130 local Disability Information and Advice Line services (DIALs) run by and for disabled people. They have information on direct payments on their website

http://www.dialuk.info/info_service/Information/independent_living.asp

Direct Payments Scotland use to offer advice and support with receiving direct payments. Although this service no longer exists, they still have useful information on the following website-

http://www.dpscotland.org.uk/

The Scottish Government website has further information for those think of or already receiving direct payments-

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

The following website DirectGov provides information on public services, including a guide on direct payments-

http://www.direct.gov.uk/CaringForSomeone/MoneyMatters/MoneyArticles/fs/en?CONTENT_ID=10018531&chk=KUeB5l
After 16- what’s new? is a website for teenagers and young people who have disabilities but is also useful for parents to refer to. The following webpage outlines relevant legislation (across the UK) that affects young people and their rights -


If an item is marked as available from the NAS please contact:

NAS Publications
Central Books Ltd
99 Wallis Road
London E9 5LN
Tel: +44 (0)845 458 9911
Fax: +44 (0)845 458 9912
Email: nas@centralbooks.com
Online orders: www.autism.org.uk/pubs

If you require further information please contact the NAS Autism Helpline
Tel: 0808 800 4104
autismhelpline@nas.org.uk

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