

## **Direct Payments for Disabled Children and Young People and their Families**

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### **Special thanks to:**

Stephen Harris and Marie Fitzgerald

### **Legal Entitlements & Problem-Solving (LEaP) Project**

LEaP is an innovative problem-solving project that helps families of children with brain conditions cope with the legal barriers they face.

We listen to families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent families getting access to services and we develop innovative ways of solving those problems. We aim to reach as many families as we can by sharing our solutions as widely as possible.

### **School of Law & community engagement**

Community engagement is fundamental to the ethos of the School of Law at Leeds University. Students are given every encouragement and support to use their legal skills to benefit the local community. In doing this students develop these skills and deepen their understanding of the role of the law in the real world: the central role of the law in fostering social justice. In furtherance of this aim the School supports (among other initiatives) a number of law clinics and the Cerebra LEaP project.

# Cerebra Legal Entitlements and Problem-Solving (LEaP):

## Cerebra & the LEaP Project

In 2014 Cerebra, a unique charity set up to help improve the lives of children with neurological conditions, endowed a research Chair in Law to support disabled children and their families experiencing difficulties in accessing their statutory entitlements to care and support services. The project is now based at the School of Law, Leeds University and the research programme titled the [Legal Entitlements and Problem-Solving \(LEaP\) Project](http://w3.cerebra.org.uk/research/university-of-leeds-cerebra-legal-entitlements-and-problem-solving-project/).

Details of the programme and past research outputs can be accessed at: <http://w3.cerebra.org.uk/research/university-of-leeds-cerebra-legal-entitlements-and-problem-solving-project/>

Both the School of Law and Cerebra receive requests from disabled people and their families for advice and support. Where these requests come within the terms of the Cerebra LEaP Project, they are assessed by the Cerebra in-house research unit and those cases which meet the LEaP eligibility criteria are referred to the Project Team for consideration. We listen to disabled people and their families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent them from getting access to services and we develop innovative ways of solving those problems. A key approach to tackling a commonly occurring problem is to commission research which benefits from the School of Law's excellent student '*pro bono*' researchers. We aim to reach as many disabled people and their families as we can by sharing our solutions as widely as possible.

As well as helping individual disabled people and their families, the Project generates vital information for the wider programme. The research is aimed at improving our understanding of the difficulties faced by disabled people and their families in accessing support services and learning how these problems can be resolved effectively. The team uses the research data (which is held securely and anonymised) to study practical problem-solving techniques and identify which approaches work best, with a view to refining the way we provide advice and disseminate good practice findings for the wider public benefit.

## Background and impetus for the research

This report and the research it is based on arose from an earlier project concerning the 'Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants'.<sup>1</sup> That report noted that many families – even if they got a much needed home adaptation (with the benefit of a Disabled Facilities Grant) – were still 'barely coping' – due to the inadequate care and support they were receiving from the local authority. As the report noted:

- [at para 5.27] "In two cases the families referred to the failure of the social services authority to provide suitably skilled care assistants to support the disabled young

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<sup>1</sup> L Clements and S McCormack *Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants: a Small Scale Pilot Study* (School of Law Leeds 2017).

person while the parents looked after needs of their other children. The result in both cases was that this support was rejected as the use of unskilled workers had exacerbated the young person's challenging behaviour. Family comments on this issue included:

Because of the failure to provide us with the care package he requires – ie trained / specialist care assistants who can manage his care needs – we have had no support. He needs 2:1 care and we do this 24 x 7. In this respect the local authority has actually saved money by not providing the suitable assistance

At the moment he has a care package of [number] hours as a direct payment (ie 2 people [number] hours a week as he needs 2:1 care) but for most of the time I am unable to find anyone suitable and/or able to help. The hourly rate of the direct payment is £7.50

We just 'cope'. We have other children and it has clearly restricted the time we can devote to them and their opportunities. We had to stop working and even a small activity, like our youngest going to the theatre requires military planning as it would mean there would only be one of us left with our son."

- [at para 5.24 a family described their situation as] "'We are on a cliff edge and begging for help' ... 'we are hanging in the balance'. Three months after the interview the family notified the research team that the authority had provided a formal response but had failed to address the need for adaptations and as a result the young person was now a 'Looked After Child' accommodated by the local authority".

Here, the adequacy of the Direct Payment system (including the rates of payment) is considered in more detail and we report on research carried out with families with disabled children and local authorities. We asked families about their experiences of using Direct Payments and about the level of payments specifically. 60 English social services authorities were also asked about their policy and practice regarding wages for personal assistants (PAs), via a Freedom of Information (FOI) request.

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## Key Messages

1. The survey reveals deep levels of dissatisfaction with the way that Direct Payment arrangements are been administered by local authorities (para 5.59).
2. Rates of pay for Personal Assistants (PAs) were very low, typically at minimum wage rates. It appears that in consequence that in many local authority areas there is a serious 'market failure' – such that authorities are arguably in breach of their statutory and public law obligations to families with disabled children (para 1.14).
3. Getting an assessment of needs was often said to be a matter of chance, with some families learning about services through word of mouth and some reporting a wait of as long as two years to get an assessment (para 5.03).
4. Many respondents commented that Direct Payment rates were too low to employ suitable PAs despite their local authority being willing to pay much higher rates for agency staff (para 5.17 – 5.18).
5. The difficulty of finding suitable staff who were prepared to work for the rates imposed by local authorities was a major and reoccurring theme of the survey (para 5.32) as was fear by respondents of losing the Direct Payments if they were not able to find such staff (5.32; 5.45).
6. The complexity of some children's support requirements, in conjunction with poor conditions of employment, meant that many families reported finding it impossible to recruit PAs. In conjunction with increased restrictions on the permitted use of money, this could result in money being unspent (para 5.47).
7. Money that remained unspent was usually reclaimed by local authorities after periods of time that ranged from two weeks to two years, leaving families without any support. There was only one report (from 256 replies) of pay rates being increased in order to promote recruitment of a PA (para 5.47).
8. There was a lack of knowledge as to how Direct Payments were calculated and indeed what the actual rate was in individual cases (paras 5.09; 5.12; 5.14; 5.20).
9. There are considerable shortcomings in realising the original intentions behind Direct Payments. Strict rationing of resources is resulting in families experiencing stress, an acute lack of support and prolonged 'battles' to secure basic services that they are entitled to by law.

## 1. Introduction

### The Purpose of Direct Payments

- 1.01 Direct payments are monies paid to disabled people (adults and children) and to carers by local authorities, to cover the cost of the care and support they are assessed as needing in everyday life. Payments are the financial equivalent to services provided directly by local authorities, with the intention of allowing recipients more scope to use the money effectively and in ways that met their needs.
- 1.02 Local authority Direct Payments to disabled people aged between 18 and 65 became lawful in 1997<sup>2</sup> following a sustained campaign by disabled people for accountable assistance.<sup>3</sup> Until 1996, it was generally unlawful for social services authorities to pay money directly to disabled people and carers in lieu of services, although a few authorities had a way of achieving this outcome by using what had come to be termed 'third party payments'.<sup>4</sup> The Community Care (Direct Payments) Act 1996 empowered local authorities to make Direct Payments, albeit that initially these were only possible for disabled adults under 65.

### Eligibility

- 1.03 Today, local authorities have a duty to make Direct Payments to almost all disabled people and carers. Payments are however only, in general, available if the disabled person or the carer has been assessed as being eligible for care and/or support by their local authority. Payments in respect of the eligible needs of disabled children under the age of 16 are paid to their parents.
- 1.04 Although Direct Payments are now part of mainstream service provision, it is important to recall that the demand for choice and control over how money was spent came from disabled people themselves. Faced with the prospect of being placed in residential care, or being allocated a service without much say in how it was provided, Direct Payments represented an important route to freedom.

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<sup>2</sup> Community Care (Direct Payments) Act 1996.

<sup>3</sup> See for example, C. Barnes *'Direct Payments' for Personal Assistants for Disabled People: a key to independent living?* (2007). In 1988 the Department of Health and Social Security (DHSS) created the Independent Living Fund (as an independent trust) to provide Direct Payments to severely disabled people who suffered significant financial loss as a result of the abolition of supplementary benefits 'additional requirements' payments in that year – see Means, R & Smith R *Community Care Policy and Practice* (Macmillan 1994).

<sup>4</sup> Minister for Health, John Bowis, at col 380 House of Commons Hansard 6.3.96 and see generally In *R (A & B) v. East Sussex County Council No 1* [2002] EWHC 2771; (2003) 6 CCLR 177.

## Choice and Control

1.05 The intention of the disabled people's campaign for Direct Payments was to increase choice and control over processes as well as outcomes; in other words, to define life goals as well as how those goals should be met. This is now a right enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – which the UK ratified in 2008. Article 19 recognises 'the equal right of all persons with disabilities to live in the community, with choices equal to others' and places emphasis on the role of personal assistance in realising this right. The General Comment to Article 19<sup>5</sup> states that state funding for personal assistance:

must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. (para 16(D)).

1.06 The General Comment also requires that states are also obliged to:

provide adequate support services to family carers so they can in turn support their child or relative to live independently in the community. This support should include respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers, who often live in situations of extreme poverty without the possibility of accessing the labour market. (para 67)

1.07 The UK, by its ratification of the UNCRPD, accepted that it was bound by its provisions. Although it has not yet been formally incorporated into domestic law, the courts have made reference to it in several judgments<sup>6</sup> and in relation to the Care Act 2014 duty to promote individual well-being the Government has stated that this is:

intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention). Supporting people to live as independently as possible, for as long as possible, is a guiding principle of the Care Act.<sup>7</sup>

1.08 At the same time as legal rights to choice and control have been strengthened, a number of factors have influenced how Direct Payments have actually been put into practice. 2012 research<sup>8</sup> found that Direct Payments had beneficial impacts on the quality of life of disabled people, including disabled children and families – with many

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<sup>5</sup> Committee on the Rights of Persons with Disabilities *General comment on article 19: Living independently and being included in the community* Eighteenth session 29 August 2017.

<sup>6</sup> See, for example, *Burnip v Birmingham City Council* [2012] EWCA Civ 629; *R (Bracking and others) v Secretary of State for Work and Pensions* [2013] EWCA Civ 1345, (2013) 16 CCLR 479; and *Cameron Mathieson v Secretary of State for Work and Pensions* [2015] UKSC 47.

<sup>7</sup> Care and Support Statutory Guidance to the Care Act 2014 (2018) para 1.19.

<sup>8</sup> Arskey, H. and Baxter, K. 'Exploring the Temporal Aspects of Direct Payments' *British Journal of Social Work* (2012) 42(1), 147–164.

reporting that they had improved their ability to exercise choice and control, as well as their sense of well-being.<sup>9</sup> These findings have been mirrored by more recent studies.<sup>10</sup> This, combined with findings that at least some aspects have led to cost savings, has driven the expansion of other forms of payments, such as personal budgets (not discussed in this report).

### **Implementing Direct Payments**

- 1.09 In 2007, a large national study<sup>11</sup> reported on the implementation of Direct Payments. Researchers found considerable variation in the amounts paid in different parts of the UK, with rates lower in Northern Ireland and Wales compared with England and Scotland (and variations within England). Although this was a wide-ranging review, the researchers reported concerns about the rates being generally too low to allow Direct Payment users a fair stake in the market. The report noted that difficulties in recruiting personal assistants (PAs) had been identified in a number of studies, as well as in their survey. This demonstrates that low rates of pay existed even before the impact of austerity (which followed the 2008 financial crisis). The research emphasised the importance of reasonable pay and flexibility so that higher rates could be paid where needed, for particular reasons.
- 1.10 It is noteworthy that there is a lack of specific research into the experiences of families with disabled children. One study,<sup>12</sup> the results of which were published in 2007, considered the experiences of families with disabled children in one local authority, and reported beneficial outcomes. Flexibility in the way that money could be used and the benefits of improved choices were noted. What is clear, in relation to the present study, is the different context. The 2007 report notes, for example, that local authorities recruited recipients of Direct Payments to publicise the provision to other potential applicants.

### **Impact of Austerity**

- 1.11 Most research on Direct Payments is concerned with the situation of adults rather than children and families. That research has emphasised the major problem of

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<sup>9</sup> Arskey, H. and Baxter, K. 'Exploring the Temporal Aspects of Direct Payments' *British Journal of Social Work* (2012) 42(1), 147–164 at 160.

<sup>10</sup> See for example, Glasby, J. and Littlechild, R. *Direct Payments and Personal Budgets: Putting Personalisation into Practice*, (3rd ed.) (Policy Press 2016).

<sup>11</sup> Davey, V., Fernández, J.L., Knapp, M., Vick, N., Jolly, D., Swift, P., Tobin, R., Kendall, J., Ferrie, J., Pearson, C., Mercer, G. and Priestley, M. *Direct Payments: A National Survey of Direct Payments Policy and Practice* (PSSRU 2007).

<sup>12</sup> Blyth, C. and Gardner, A. "We're not asking for anything special': Direct Payments and the carers of disabled children' *Disability and Society* (2007) 22(3), 235-249.

reduced social care funding at a time of increasing demand for services.<sup>13</sup> Although legislation was passed in the 1990s, there was a considerable delay before Direct Payments became commonplace. This period of increased ‘take up’ coincided with the onset of austerity economics, with documented detrimental effects on adults. Problems noted include: difficulties with gaining access to information about services (including Direct Payments); restrictions in the permitted use of funds; a poor alignment of care needs and services;<sup>14</sup> difficulties with getting payments put into effect; problems with managing PAs; and with the administration of such payments.<sup>15</sup>

1.12 At the same time, research has also found evidence of worsening employment conditions for workers in the social care field. This has been particularly acute for workers employed by private agencies, where increased use of zero hour contracts and sub – minimum wage rates has attracted criticism.<sup>16</sup>

1.13 It is now widely accepted that there is a ‘crisis in social care’.<sup>17</sup> Before looking at the results of the Cerebra survey, we consider the legal position with regard to Direct Payments and the methods used for the study.

### **Personalisation and market shaping**

1.14 ‘A hallmark of a poorly functioning personalisation market’ is – in the words of Malbon et al:<sup>18</sup>

a ‘thin market’, which occurs when there are zero or very few providers of a certain service in a local area, or if the available service providers are full and cannot take on more participants.

1.15 Although Malbon et al are describing the market failure confronting the Australian National Disability Insurance Scheme, their analysis strongly resonates with the findings in this report. As they note ‘further entrenching disadvantage for people who experience thin markets, spending restrictions ... means that money .... unspent by participants may be reclaimed’. This is well known, and in relation to adults in need the Care Act 2014 section 5 places a duty on local authorities to:

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<sup>13</sup> Pearson, C. and Ridley, J. ‘Is Personalization the Right Plan at the Wrong Time? Re-thinking Cash-for-Care in an Age of Austerity’ *Social Policy and Administration* (2017) 51(7) 1042–1059.

<sup>14</sup> Malli, M.A., Sams, L., Forrester-Jones, R., Murphy, G. and Henwood, M. ‘Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature’ *Disability & Society*, (2018) 33(9) 1412-1435.

<sup>15</sup> Katzman, E.R. and Kinsella, E. ‘It’s like having another job’: the invisible work of self-managing attendant services’ *Disability & Society*, (2018) 33(9), 1436-1459.

<sup>16</sup> Hayes, L.J.B. and Moore, S. ‘Care in a Time of Austerity: the Electronic Monitoring of Homecare Workers’ Time, Gender, Work and Organization, (2017) 24(4) 329 – 345.

<sup>17</sup> Association of Directors Adult Social Services (ADASS) *Budget Survey 2019* page 5 and see also Local Government Association *Survey of council finances* (July 2019).

<sup>18</sup> E Malbon, G Carey and A Meltzer ‘Personalisation schemes in social care: are they growing social and health inequalities?’ in BMC Public Health 2019 19:805 citing G Carey et al *The Vexed Question of Market Stewardship in the Public Sector Social Policy & Administration*. (2018) 52(1) pp387–407.

promote the efficient and effective operation of a market in services for meeting care and support needs with a view to ensuring that any person in its area wishing to access services in the market—

- (a) has a variety of providers to choose from who (taken together) provide a variety of services;
- (b) has a variety of high quality services to choose from;
- (c) has sufficient information to make an informed decision about how to meet the needs in question.

1.16 The findings in this report strongly suggest that there is a severe market failure in many local authority areas. It would appear therefore that the Secretary of State in England is under a public law duty to have regard to these findings and to consider taking action to address this failure. One material consideration would be the exercise of his powers of direction under Local Authority Social Services Act section 7D. This may also be the case in relation to the use by the Scottish and Welsh Ministers, and the Northern Irish Secretary of their statutory default powers.

## 2. The Law on Direct Payments

2.01 This section briefly describes the legal basis for Direct Payments for the social care needs of disabled children and their carers.<sup>19</sup>

### England

2.02 The Community Care (Direct Payments) Act 1996 enabled social services authorities to make Direct Payments to cover the costs of the eligible social care needs of disabled adults. In 2000 the scheme was extended (by way of an amendment to the Children Act 1989<sup>20</sup>) to include disabled children and in the same year the 1996 Act was amended<sup>21</sup> to include carers. The 1996 Act has been repealed<sup>22</sup> and the provisions as they relate to adults in need and their adult carers' are now found in the Care Act 2014, but for disabled children – the Children Act 1989 remains the relevant statute.

2.03 The 1989 Act states that Direct Payments must be paid at a rate the local authority considers 'to the reasonable cost of securing the provision of the service concerned'.<sup>23</sup> The relevant Government guidance explains that this means that they should be 'sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service to which the payments relate'.<sup>24</sup> In estimating what this cost should be – the guidance states that (at para 114):

councils should include associated costs that are necessarily incurred in securing provision, without which the service could not be provided or could not lawfully be provided. The particular costs involved will vary depending on the way in which the service is secured, but such costs might include recruitment costs, National Insurance, statutory holiday pay, sick pay, maternity pay, employers' liability insurance, public liability insurance and VAT. Some councils have found it helpful to include a one-off start-up fund within the direct payments to meet these costs as well as other forms of support that might be required, such as brokerage, payroll services and Criminal Records Bureau checks on employees.

2.04 The guidance also notes that a 'preventive strategy may necessitate a higher investment to achieve long-term benefits and savings. Provision of Direct Payments that allow a person to remain in their own home may represent long-term savings' (at para 118).

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<sup>19</sup> Detailed guidance concerning the operation of the Direct Payments process for disabled children in England is contained in the Department of Health / Department for Children, Schools and Families *Guidance on direct payments for community care, services for carers and children's services England* 2009.

<sup>20</sup> By the Carers and Disabled Children Act 2000 section 7, which a new section (17A) into the 1989 Act.

<sup>21</sup> By the Carers and Disabled Children Act 2000 section 5.

<sup>22</sup> The Act was repealed by the Health and Social Care Act 2001 and the relevant provisions relating to Direct for adults and adult carers in England now derive from the Care Act 2014 s31-33.

<sup>23</sup> Children Act 1989 s17A3A.

<sup>24</sup> Department of Health / Department for Children, Schools and Families *Guidance on direct payments For community care, services for carers and children's services England* (2009) para 111.

## Wales

- 2.05 Direct payments are available in Wales on a similar basis to those in England. The key statute is the Social Services and Well-being (Wales) Act 2014 and the detail of the scheme in Wales is spelled out in regulations<sup>25</sup> and in guidance in the [Part 4 Code of Practice \(Meeting Needs\)](#).

## Scotland

- 2.06 Direct payments are available in Scotland on a similar basis to those in England. The key statute is [The Social Care \(Self-directed Support\) \(Scotland\) Act 2013](#) which has been fleshed out by regulations<sup>26</sup> and detailed [Statutory Guidance to accompany the Social Care \(Self-directed Support\) \(Scotland\) Act 2013](#).

## Northern Ireland

- 2.07 Direct payments are available in Northern Ireland on a similar basis to those in England. The key statute is [The Carers and Direct Payments Act \(NI\) 2002](#)<sup>27</sup> for which detailed guidance has been issued by the Department of Health, Social Services and Public Safety - namely [A Guide to Receiving Direct Payments](#) (2008).

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<sup>25</sup> The Care and Support (Direct Payments) (Wales) Regulations 2015.

<sup>26</sup> The Self-directed Support (Direct Payments) (Scotland) Regulations 2014.

<sup>27</sup> And the Children (Northern Ireland) Order 1995 Article 18C.

### 3. Methods

3.01 Two parallel investigations were carried out:

- A survey of local authority hourly pay rates for Direct Payments.
- A survey of family members' experiences of using Direct Payments.

Methods for each of these are described in turn. The two pieces of work are best seen as independent of one another because of differences in the sample population. Therefore we have not made comparisons when discussing the findings later in the report.

#### Survey of Local Authorities

3.02 Students at the University of Leeds carried out this part of the study,<sup>28</sup> which involved sending Freedom of Information (FoI) requests to 60 social services authorities in England, about their hourly Direct Payment rates for disabled young people and disabled adults (see Appendix 1 for the questions asked). Authorities were chosen at random, selected from lists designed to provide a geographical mix that included unitary authorities, County Councils, Metropolitan and London boroughs. The FoI requests were sent out in November 2017 and responses closed at the end of December that year.

3.03 A total of 52 responses were received from the 60 Local Authorities who were contacted. Of these, 49 replied adequately to the questions. Three Local Authorities replied but were not included either because they stated that there was no agreed rate or they did not state whether the amounts given were net or gross payments.

3.04 Although participants were asked about both adults and children, in this report we discuss the responses in relation to children only.

#### Survey on Family Experiences of Payment Rates and of Using Direct Payments

3.05 A Survey Monkey<sup>29</sup> questionnaire was developed and circulated by Cerebra. It asked family members about payment rates for PAs as well as about family experiences of using Direct Payments. A total of 256 replies were received to the survey and of these, 218 were complete, answering all the questions. 206 respondents provided details of the local authority area in which they lived, 83% (171) were based in England: 3% (7) in Scotland; 13% (26) in Wales and 1% (2) in Northern Ireland (see para 5.54 and Appendix 4 below).

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<sup>28</sup> University of Leeds – [Cerebra Legal Entitlements and Problem-Solving \(LEaP\) Project](#).

<sup>29</sup> <https://www.surveymonkey.com/>.

- 3.06 As well as giving answers to closed questions, respondents were also given the option of adding comments to explain more about their experiences. Many did so and these reveal more about the nuances of their replies.
- 3.07 It is important to point out some considerations in relation to the survey. Families interpreted the questions on children as being about their sons and daughters, regardless of age. Therefore the data includes reference to some who were legally adults at the time of taking part. However, the same parents also described their experiences over time and this included experiences from when sons and daughters were under 18.

## 4. The survey of local authorities

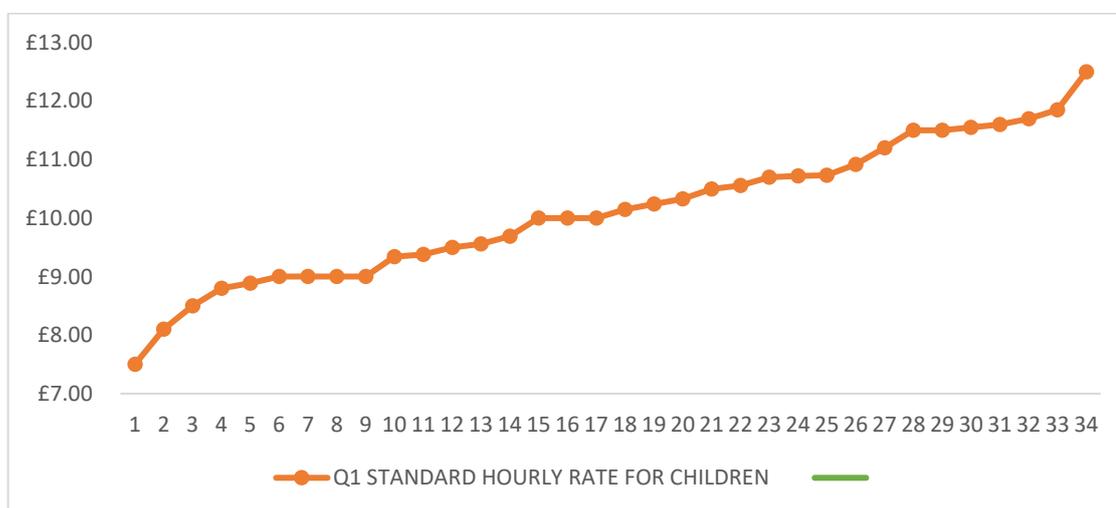
4.01 In this section, we discuss the answers given to the FOI request.

4.02 The first question asked:

**What is the standard hourly rate paid by your local authority for a Direct Payment for disabled child assessed as requiring personal care support under the Children Act 1989 Part 3?**

4.03 47 replies were received to this question. Gross amounts ranged between £8.71 and £12.96 and net amounts between £7.50 and £10.90 and the average was £10.57. A graphical chart of the gross amounts is provided as Table 1 below.

**Table 1: Hourly gross rates paid to personal assistants of disabled children**



**Table 1**

Note: the numbers on the lower axis refer to individual authorities. The amounts stated are as given by the local authorities.

4.04 Several local authorities provided a breakdown of what was included in the amounts, but not all did so. Therefore the figures should be taken as indicative, as it is not possible to be certain that all authorities reported the amounts in exactly the same way. For example, a few mentioned that the gross figure did not include Employer's Liability/Public Liability insurance, which they said was paid separately. Another noted that the costs of DBS checks<sup>30</sup> were also met separately.

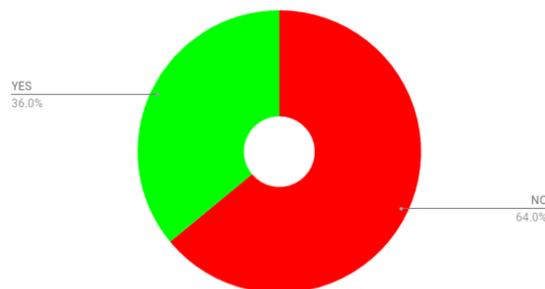
<sup>30</sup> The Disclosure and Barring Service (DBS) provides details of an applicant's criminal convictions, , cautions, warnings and reprimands.

4.05 The important point to note, despite such variations, is that PAs were paid at a low rate<sup>31</sup> that was at, or very close to, the minimum wage.<sup>32</sup> One local authority noted that even with an official £12.50 rate, the maximum a PA could be paid was £9.50 because of the additional costs involved. Many mentioned enhanced rates were available if the rate was not enough to meet needs and this decision would be assessed by a Panel.

4.06 Councils were then asked the following question:

**Does your council have a policy for increasing the sum specified in answer 1 above in cases where the cost of meeting the disabled child's assessed needs cannot reasonably be met by a payment at the hourly rate specified in answer to question 1?**

4.07 Most local authorities said that they did not have a policy for increasing the amounts paid for personal assistance for children (32 said they did not, compared with 18 local authorities that said they did). This did not mean that pay increases were not granted, just that there often did not seem to be a transparent process for doing so.



**Table 2**

Percentage of local authorities stating they had a policy on PA payment rates for children

4.08 Local authorities were also asked to provide a copy of their policy. Of the 18 that said they had a policy, 11 provided it. Those who did not mainly indicated that decisions were taken on a case by case basis or were decided in line with statutory guidelines.

<sup>31</sup> See Appendix 2 below for the calculation of the minimum amounts that can lawfully be paid: that as a generalisation, the on-costs of employing a PA amount to about 23% over and above wages paid to the worker: so that even an hourly rate of £12 (at the upper end of the gross payment rates disclosed) would only enable a payment to the worker of about £9.00 per hour.

<sup>32</sup> See Appendix 2 below for details of the minimum wage rates at the time of the survey.

## 5. Survey of Families

5.01 This section discusses the data from the survey of family members. The questions asked in the survey as a whole are listed in Appendix 3. Although this part of the report follows the structure of the survey, the data has been re-organised to make it more readable as a report and to make the findings clearer. Following this we discuss the implications of the data (see chapter 6 below).

5.02 Question 1 asked:

**Which of the following applies when you were told that social services agreed that you needed support services?**

ANSWER CHOICES	RESPONSES
The local authority offered us direct payments for some/all of the support needs and we accepted	65.49% 167
The local authority offered us direct payments for some/all of the support needs but we turned the offer down	2.35% 6
The local authority didn't offer direct payments but we requested them for some/all of the support needs and they agreed	22.35% 57
The local authority didn't offer direct payments but we requested them for some/all of the support needs: however, they refused our request so we don't receive direct payments (please explain briefly the reasons they gave in the box below)	2.75% 7
I didn't know about direct payments and the local authority didn't inform me about them	7.06% 18
<b>TOTAL</b>	<b>255</b>

**Note:** One respondent did not reply. All percentages in this and other data tables are percentages of the replies received rather than all of those who responded (valid percent).

5.03 Family members were also invited to comment on this question and 76 did so. Replies indicated considerable stress and crisis experienced by families and most were highly critical of local authority support. By far the largest number of comments described problems of getting an assessment and being deemed eligible. 10 of the 76 families said that they had problems finding out about Direct Payments: getting the information from friends, teachers or other local services rather than social workers. Many experienced considerable delay in getting assessed and being deemed eligible (24 reported severe problems), with some having to try to get an assessment several times before being deemed eligible. Delays of two years or more were reported and in some instances family members had been or were in formal dispute, including

legal proceedings, securing the intervention of an MP and initiating formal grievance procedures. By way of example, three comments on the procedures included:

We had to fight to get a social worker to make an assessment. My husband works as a social worker so knew our rights but even he found it extremely difficult to get access to an assessment.

I was forced to take Direct Payments or have no support at all ... I was threatened if I did not take just 25hrs of Direct Payments that the local LA would remove my son from my care. Previously high court decided he needs 2-1 care 24/7. The LA stopped this 2 years ago even though both his physical and learning health has deteriorated and [he has had] more brain surgeries.

At the moment it would seem the whole system is collapsing from health, education and social services. I just keep getting told there is nothing else they can offer me, and there are no funds to help us. The social services won't even let me have a carer's assessment or child in need assessment. [The] services are a disgrace at the moment.

- 5.04 Cost cutting was clearly identified as problematic, especially for more recent applicants, who commented on insufficient hours. Lack of choice was another theme of these comments, with many offered Direct Payments on a 'take it or leave it' basis. Other problems identified included a lack of support with managing the process of recruitment and management and several noting the difficulties of finding the right kind of PA support.
- 5.05 Problems with assessment are also a recurring theme in previous research on Direct Payments.<sup>33</sup> Limiting the number of people who are assessed as eligible for support is one way that local authorities can contain their costs – and this factor is not an isolated finding.<sup>34</sup> Our research however shows just how far the situation has now moved from meeting the intention of Direct Payments to enable choice and control and independent living. Getting an assessment and support was described by several people who provided comments as 'a battle'.
- 5.06 Question 2 asked, (for those it applied to):  
**Why did you decide not to have Direct Payments? (Please tick all the boxes that apply - you can tick more than one box).**
- 5.07 Just six respondents answered this question (250 skipped it). Between them they ticked a total of 10 boxes and of the answers they gave; five said that they did not want the responsibility of managing Direct Payments, four said that they could not

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<sup>33</sup> See for example Blyth, C. and Gardner, A. "We're not asking for anything special': Direct Payments and the carers of disabled children' *Disability and Society* (2007) 22(3), 235-249 and Welch, V et al *Child: care, health and development* (Blackwell Publishing Ltd 2011) 38, 6 [Using direct payments to fund short breaks for families with a disabled child], 900–909.

<sup>34</sup> See for example L Clements and S McCormack *Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants: a Small Scale Pilot Study* (School of Law Leeds 2017) and Blyth, C. and Gardner, A. "We're not asking for anything special': Direct Payments and the carers of disabled children', *Disability and Society* (2007) 22(3), 235-249.

find suitable support staff and one said that the amount offered as a Direct Payment was insufficient.

5.08 Question 3 asked:

**Does your local authority offer a managed account service? (This is where the local authority, or another organisation funded by the local authority, pays your staff or the agency you use and deals with things like tax and national insurance on your behalf).**

5.09 219 answered this question and 37 skipped it. Answers were as follows:

ANSWER CHOICES	RESPONSES	
Yes and we use, or will use, the managed account service	36.99%	81
Yes but we don't, or won't, use the managed account service	26.03%	57
No	22.83%	50
Don't know	14.16%	31
<b>TOTAL</b>		<b>219</b>

5.10 Just over a third of families said that there was a local authority support service and that they used it. Comments were also invited and there were 26 responses. Just one comment spoke positively of the support service, while seven made neutral comments and 12 identified problems. The main problems identified were to do with poor quality of service. For example: being 'unresponsive and under-resourced' and five mentioned the cost of the service (see in this respect para 5.12 below). Of those identifying problems with the service, it was noted that quality had declined rather than improved over time.

5.11 Question 4 asked:

**Are there charges to you for using the managed account system?**

5.12 81 answered this question and 175 skipped it. 41 added comments. Of those answering, 42% stated they were charged – with sums of between £20 – £30 per month. 41% said they were not charged and 27% said they did not know. Some families were unclear about the amounts, often because the costs were deducted by the local authority before being issued (net payments). The time spent by recipients was not accounted for and several commented that managing payments entailed considerable work. Although most appeared clear about the arrangements, a small

number mentioned feeling uninformed and embarrassed to ask for help or being too busy to take time to understand the complexities.

5.13 Question 5 asked:

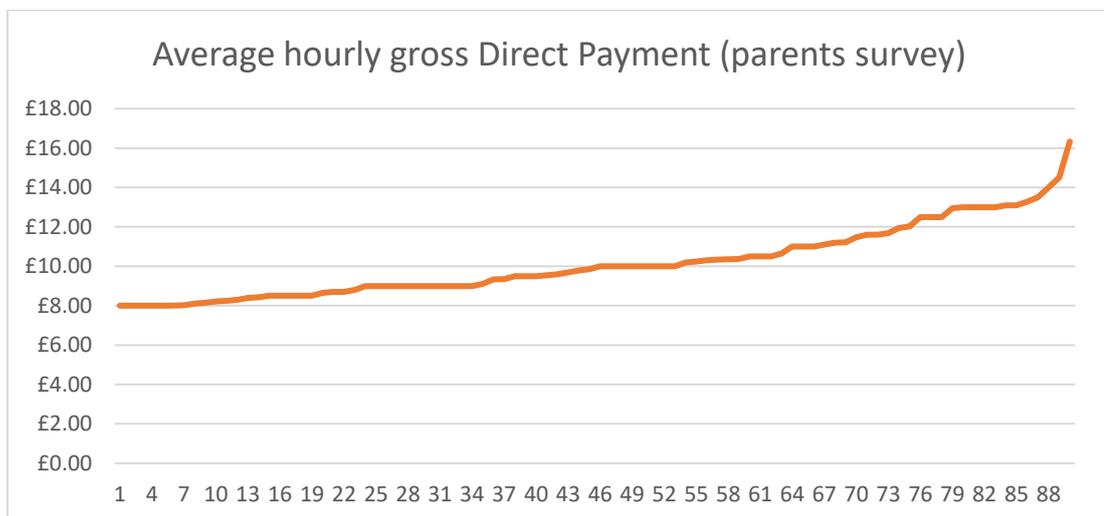
**Do you know the standard hourly rate (or rates) on which your local authority calculate your Direct Payment?**

5.14 181 respondents answered this question and 75 skipped it. 60% stated that they did know the rate but 40% stated they did not. It was not immediately clear why this was not known.

5.15 Question 6 asked:

**If yes, what is the hourly Direct Payment rate? Some authorities pay one rate if you use an agency (e.g. a registered care provider) and another if you employ a personal assistant yourself. If you use an agency and employ a personal assistant and you know what these rates are please give both. Otherwise, simply give the one you are paid.**

5.16 91 respondents provided details of the gross amount they received in order to employ a PA. The hourly weekday rates ranged from £8.00 to £16.33 (this high rate was awarded to enable British Sign Language signers to be employed - otherwise the second highest rate was £14.00). The average rate was £8.90 and the range is shown in Table 3 below:



**Table3**

5.17 Comments included:

- '£9.35 gross includes employer costs but £8.25 is what we are allowed to pay PAs. We used to get the agency rate but that was removed on reassessment. Now we can't find any PAs to work for £8.25';

- '£11.60 direct payments hourly rate. As we could not recruit staff we employed an agency (worker) at £14.70 per hour. The local authority did not meet the increased cost initially, but then commissioned the agency to provide the care. We don't know the agreed rate';
- 'It was a fight to find out though. They capped the PA rate at £7.90 per hour until September 2017, £8.15 since (then) but this makes it impossible to recruit and retain staff to deal with a teenager with severe complex needs. They seem to have no agency cap and would pay out £280 per night to respite'.

5.18 One respondent who no longer received a Direct Payment made the following comment:

'We challenged this. We could not get a carer for complex needs for £10 for one hour. We swapped to commissioned care. They now pay an agency £26 per hour for four hours but [the] carer only has to work one hour and they pay all mileage'.

5.19 Question 7 asked:

**Does the hourly rate paid by your local authority include such items as national insurance, holiday pay, sick pay and employers' liability insurance?**

5.20 70% answered with Yes and 30% with No, indicating that gross payments were more frequent among those replying to the survey. However comments to this question indicated a considerable amount of uncertainty. Replies such as 'I think so' gave the impression of lack of certainty. Some were more directly critical – for example: 'Yes, it is supposed to cover this, but in practice does not', or even, 'It does not include these, and the resulting rate is not fit for purpose'.

5.21 There were indications that some expenses were not included and that the national legal requirements for employment and the amounts that local authorities were willing or able to pay were different. For example – one person stated:

We have to pay for employees' PVG<sup>35</sup> checks here ourselves too from our budgets, so they are very tight, soon to be compulsory pensions too and our budgets are not increasing.

5.22 Question 8 asked:

**How much do you, or will you, receive in Direct Payments per month in total? (If you don't know the figure, what do the Direct Payments pay for? – e.g. 4 hours of PA support during school term time and 8 hours during the school holiday).**

5.23 A total of 206 respondents gave an answer to this question. The majority - 130 respondents – gave the number of hours worked and most stated the hours worked

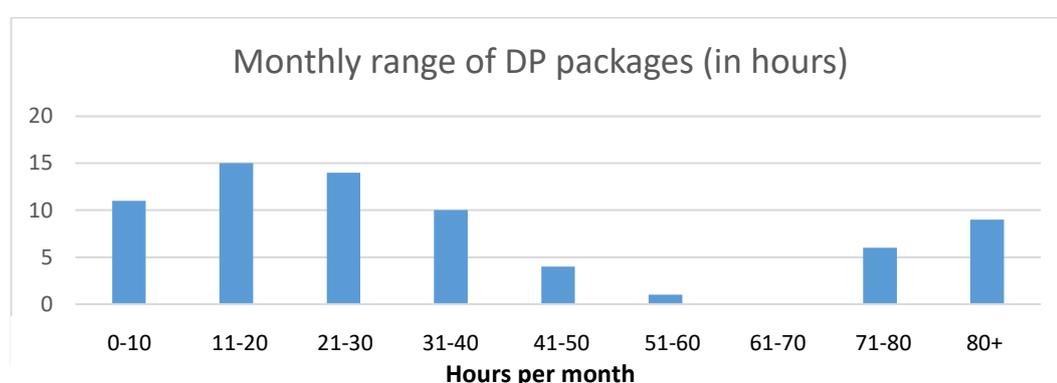
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<sup>35</sup> Protecting Vulnerable Groups check apply in Scotland. They are equivalent to Disclosure and Barring Services 'DBS' in England and Wales. Both involve a search of a job applicant's history of criminal convictions, whether spent or unspent, cautions, warnings and reprimands.

per week. Others gave the hours worked per month and in order to make the figures comparable, weekly totals have been multiplied by four. It is important to note therefore, that the amounts below therefore give an indication rather than an exact comparison. Many families also were allocated more hours during school holidays and this has been factored in to give a rough average per month and detailed in Tables 4 to 7 below.

Hours per month	Up to 10	11-20	21-30	31-40	41-50	51-60	61-70	71-80	80+
No. Respondents	16	51	21	16	6	3	1	3	13 <sup>36</sup>

**Table 4**



**Table 5**

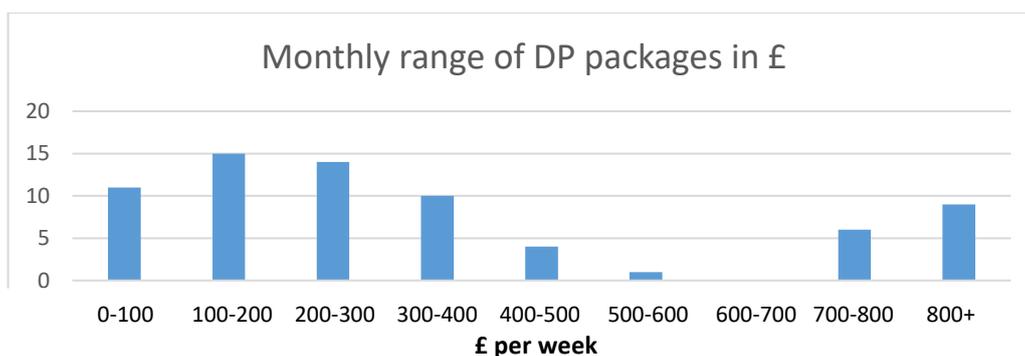
5.24 A smaller number (63) gave a figure for the amount of payment received. Because some gave both hours and amounts paid, the total number is more than the 206 replies. The figures given are detailed in Tables 6 and 7 below.

Amounts received	Under £100	£100-£200	£201-£300	£301-£400	£401-£500	£501-£600	£601-£700	£701-£800	Over £800
No. Respondents	11	15	14	10	4	1	0	6	9 <sup>37</sup>

**Table 6**

<sup>36</sup> There was a wide range in this group, as follows: 80, 88, 100 (x2), 116, 128, 132, (x2) 147, 172, 198, 210 and 720.

<sup>37</sup> The amounts paid per month over £800 were as follows: £1,000, £1,240, £1,606, £1,650, £1,760, £2,200, £2,293, £3,000, £3,200.



**Table 7**

5.25 It is clear from these figures that most families received a modest amount of PA time: of a few hours a week. A small number of families received a much larger amount of support, presumably on the basis that their child needed substantial assistance. This pattern is mirrored in the amounts paid, which show a spike in the lower amounts and another for the higher amounts with a gap between the two.

5.26 Question 9 asked:

**How do you, or will you, spend the Direct Payment? (Please tick all the boxes that apply to you - you can tick more than one box).**

5.27 192 respondents answered this question and 64 skipped it.

ANSWER CHOICES	RESPONSES	
Employing one or more personal assistant	85.42%	164
Paying an agency	14.58%	28
Paying for services directly	29.69%	57
Total Respondents: 192		

5.28 43 people added comments for this question. Of these, nine explicitly mentioned problems recruiting suitable people who were able to provide adequate support to children.

5.29 There were also issues as to how the money could be spent. Discrepancies were apparent concerning what the money could be used for in different areas. Respondents gave examples of sporting activities that their child took part in as a result of receiving Direct Payments. Another said they had been told that they could not directly pay for services – such as hydrotherapy. Restrictions, which go against the original intent of Direct Payments, where users exercise control over the means of meeting needs, appears to be the result of local authorities seeking to manage scarce resources through limiting available choices of recipients. Some respondents

were not clear about permitted use of money but said that they did not want to seek clarification for fear that their payment would be reduced or taken away, as had happened to some previously.

5.30 Question 10 asked:

**What are the things that work well, or you think will work well, in setting up and managing Direct Payments? (Please tick all the boxes that apply to you - you can tick more than one box).**

ANSWER CHOICES	RESPONSES
Flexibility	68.04% 132
We're in control	60.82% 118
We can find personal assistants with the necessary skills	42.78% 83
We can pay the agency of our choice	12.37% 24
Reliability of personal assistants	34.02% 66
It is easy to deal with short term problems - for example, finding suitably qualified cover during staff holidays or periods of sickness	6.70% 13
None of the above (Please give brief details in the box below)	14.43% 28
Total Respondents: 194	

5.31 76 people commented on this question. Eight people made positive comments on Direct Payments but very many more were critical of their experiences.

5.32 The most important issue raised was the problem of finding suitable staff. Thirty six people mentioned this specifically, with low rates of pay and inadequate access to training seen as highly problematic in a majority of cases. Reliability, continuity of staff and flexibility were also difficulties. Several respondents felt a 'threat' of having money taken away because it was not spent due to recruitment problems. While several stated that local authorities had said that they were not permitted to make recommendations about potential sources of PA assistance; this was also experienced as being left to cope alone with the challenges of recruitment. Three respondents used the phrase 'complete nightmare' to summarise the difficulties they had encountered.

5.33 Question 11 asked:

**Do you think that the total amount of Direct Payments you get is sufficient to cover all of the needs that have been identified by social services?**

5.34 195 respondents answered this question and 61 skipped it. 48% answered Yes and 52% responded with No. Comments to this question reflected a range of experiences. While some talked of having enough assistance there were also difficulties with recruitment rather than hours. In other instances, respondents talked of not having enough assistance or of having to do some tasks themselves - such as lifting - which in other circumstances were done by two paid staff. Several spoke of having to 'fight' and 'battle' to get enough help. There was a perception that provision was led by resources.

5.35 Question 12 asked:

**Do you think that the hourly rate of Direct Payments awarded is sufficient?**

5.36 194 answered this question and 62 skipped it.

ANSWER CHOICES	RESPONSES	
Yes	24.74%	48
No, it's not enough to attract suitably trained staff	34.54%	67
No, it's not enough to retain suitably trained staff	14.43%	28
Not always	20.10%	39
Other	6.19%	12
TOTAL		194

5.37 Comments on this question indicated that a few felt that amounts paid were sufficient. However, more considered amounts insufficient, especially where some particular skills were needed to do the job well. For example, one family mentioned that they did their own fundraising and that there was a lack of applications which contrasted with initial interest in the job advert:

As I fundraise for my son, he has a large following on social media with people who would like to work with him. When I advertised the role I had an impressive response. When I circulated the job description with the rate, not one person applied for the role. On follow up, feedback was that the rate was an insult.

5.38 Lack of reimbursement of travel expenses and short hours of work could also exacerbate recruitment problems. Also, PAs could potentially experience a pay cut when children moved to adult services as wages in some areas were lower. Several respondents pointed out particular problems for children whose behaviour was unpredictable or difficult – for example in recruiting competent PAs who knew what to do was especially problematic. In consequence, some relied on family members to help out, struggled on their own or gave up Direct Payments altogether.

- 5.39 Question 13 asked:  
**Have you experienced difficulties getting the local authority to agree to pay for associated costs such as essential training for personal assistants, necessary travel or other expenses incurred to meet the identified needs?**
- 5.40 185 respondents answered this question and 71 skipped it. 45% answered with Yes and 55% answered with No. There were 96 comments on this question. Most of these stated that local authorities had refused to pay for anything other than the hourly wage rate for PAs.
- 5.41 Question 14 asked:  
**Are you still in the process of setting up Direct Payments?**
- 5.42 196 respondents answered this question and 60 skipped it. 7% answered with Yes and 93% answered with No.
- 5.43 Question 15 asked:  
**Do you sometimes have trouble spending all of the allocated Direct Payments?**
- 5.44 182 answered this question and 74 skipped it. 55% answered Yes and 45% answered No. Comments were added by 114 respondents. Reasons given for returning money primarily had to do with the difficulties of recruiting PAs but could arise for other reasons. For example one respondent stated:  
My son is medically complex [and] has spent a lot of time in hospital so payments have accrued which the LA try to take back (8 week rule). Luckily my social worker does argue the case that when winter comes and we spend a lot of time at home these accrued payments are needed.
- 5.45 However, far more respondents reported a lack of flexibility on the part of local authorities. If PAs could not be recruited due to poor terms and conditions of employment, the money was taken back by the local authorities rather than being made available for such things as travel expenses - which might make employment more attractive.
- 5.46 Question 16 asked:  
**If you sometimes have trouble spending all of the allocated Direct Payments:**

ANSWER CHOICES	RESPONSES	
Are you allowed to keep it and spend it later on identified needs? (e.g the personal assistant is ill for three weeks and you can't find suitable cover; you then use the unspent money to pay for extra personal assistant support during the next summer holiday)	46.74%	43
Does the local authority take it back?	53.26%	49
TOTAL		92

5.47 92 respondents answered this question and 164 skipped it. Most local authorities took back unspent money after a certain period of time. Comments indicated a variation in the length of time that recipients were allowed to keep unspent money. Time periods ranging from two weeks (deemed to be 'deeply unhelpful') to two years were mentioned. Some indicated that different arrangements applied to money allocated for different purposes.

5.48 Question 17 asked:

**Are you allowed to 'bank'/accumulate hours? This is where, for example, you are allocated 2 hours of personal assistant support per week but don't use them for 3 weeks and then use them all to enable your child to go on a day trip.**

5.49 172 answered this question and 84 skipped it. 88% answered Yes and 12% answered No. No comments were invited for this question.

5.50 Question 18 asked:

**Have you had your Direct Payment support packet cut since it was set up?**

5.51 179 respondents answered this question and 77 skipped it. 22% answered with Yes and 78% answered with No. Comments to this question indicated that of those experiencing them, cuts had been made to the hours allocated and / or to the wages allowed for PAs.

5.52 Question 19 asked:

**Have you previously had a Direct Payment and then decided not to continue with it?**

ANSWER CHOICES	RESPONSES	
Yes (Please briefly explain why in the box below)	11.24%	20
No	88.76%	158
TOTAL		178

5.53 178 respondents answered this question and 78 skipped it. Reasons for deciding not to continue with a Direct Payment included the stress of managing all aspects of the payment. Management of pension payments, real time reporting on tax to HMRC and checking up that support agencies were managing the payments correctly posed particular problems. Others stated that their children had gone into residential care or supported living. Recruitment problems were again an important issue for those giving up Direct Payments.

5.54 Question 20 asked:  
**In which local authority do you live? (This is who you pay your council tax to) (Please leave blank if you'd rather not say).**

5.55 This information is provided in Appendix 4.

5.56 Question 21 asked:  
**How old is your child?**

Age	0-5	6-10	11-15	16-20	21-25	26-30	30+
No. Respondents	13	71	78	67	14	3	1

5.57 Most children were therefore under 18 years but a smaller number were adults and some noted differences between children's and adult services.

5.58 Question 22 asked:  
 That's all the questions we have for you but please feel free to add any comments you may have about getting and managing Direct Payments in the box below

5.59 Additional comments were left by 97 respondents, who expressed a range of views. A small number (6) were positive about their experiences of Direct Payments but four of these also noted problems. These included finding PAs (2); having money taken back (1); or a lack of alternatives if Direct Payments didn't work out. Nevertheless, one respondent stated:

DP is a lifeline I don't know how we would have managed without it in the past 10 years. It is flexible & most definitely the way forward. I would recommend it 100% [as] it gives not only us a break but my daughter time away from us. It also allows us time with other family members without having to deal with our daughters complex needs an extremely vital resource. Long may it continue.

5.60 Far more prevalent were comments emphasising problems with support arrangements. The problems included: finding out about Direct Payments and other support services; getting assessments arranged; problems with recruiting PAs; restrictions on hours and money awarded; restrictions on choice over how the

money could be spent; and a lack of support in managing the administration of payments. In order to limit repetition, these comments have been incorporated into the sections above. It is important to note the strength of feeling expressed and deep level of dissatisfaction.

- 5.61 Two additional issues were raised by respondents that have not been mentioned previously. First, there was a perception of inconsistent and unfair treatment, where some people were checked on or charged more than others:

We are lucky the care package was purposely set 'loose' so we can pick and choose the care as needed. I am aware others are constantly monitored and are simply not listened to. There is no consistent approach.

[There is a] vast variation in amounts paid in personal contributions. I have friends whose sons are on exactly the same benefits, packages and [have] less than £1000 savings who pay nothing and my son has had to pay £60 per week. Local authority will not give answers to questions. Total lack of transparency in the system for personal contributions.

- 5.62 Second, respondents pointed to poor experiences of transition from children to adult services. While this finding has been frequently reported in other research on social care services, it indicates that problems have not been solved. For example:

For our family transition has simply been a tick box exercise of mentioning support, but not identifying needs in a timely fashion, failing to put in any support initially, failing to recognise that the wrong support can cause harm to the individual and family and laying blame rather than problem solving.

- 5.63 A final additional point noted by several respondents was that local authorities were not following the legal requirements and some stated that authorities were breaking the law:

[It is] a whole process shrouded in mystery, and shifting sand that keeps changing ! DOH guidelines say that the LA can't put a blanket ban on transport but you try ... using it for that, big time trouble!!! ... This seems in direct contrast to the Care Act which actively encourages funds to be used innovatively and creatively, that LA must take a hands off approach, a light fingered one. Trust me that's entirely at odds to what is actually happening in practice. They are now making use of DP so constrained there is no room for flexibility.

- 5.64 Others said:

The intransigence of the council re rates for PA and unwillingness to properly apply the law with our only recourse being the complaints process. We need a proper means of appeal /redress [similar to the SEND tribunal].

I was told my carers needs for a second disabled child would not be taken into account as he did not meet the criteria for disabled children's team. [They] were only interested in the child with autism who met their criteria. The one with diabetes doesn't so they won't take the sleep deprivation I experience from checking his diabetes several times a night into account. This is plainly unlawful.

5.65 This section has provided a summary of the responses given by family members to the questions posed by Cerebra. The next part of this report provides an analysis of the data and discusses the implications for children and families with brain impairments.

## 6. Discussion and findings

- 6.01 In this section we aim to draw out the overall issues that arise from the data.
- 6.02 The majority of the recipients of Direct Payments in this study valued the support they received. Most opted to employ personal assistants rather than to pay for services or agency workers.
- 6.03 There is not a straightforward way of measuring increases over time but it is interesting to note that there appears to have been a significant increase in the numbers of family members receiving Direct Payments to provide care to disabled children after 2001.<sup>38</sup> There is however a dearth of more recent data on Direct Payment uptake – but rates (in England) for adults increased six-fold between 2004–05 and 2013-14, when 14.5% of all people who received community based services received them as a Direct Payment.<sup>39</sup>
- 6.04 The research discloses deep levels of dissatisfaction with the way that Direct Payment arrangements are administered by local authorities. This strongly suggests that there is an urgent need for the English Government<sup>40</sup> to undertake a fundamental review of the operation of its Direct Payment scheme.
- 6.05 The problems identified by the research findings can be summarised as:
- Lack of access to services
  - Lack of information and clarity
  - Restrictions on choice and flexibility

Each of these are discussed in turn.

### Lack of Access

- 6.06 Lack of access was apparent in the problems that family members experienced in obtaining to information about support that was available. Many previous studies have also reported problems in this respect but this was a recurring theme among parents taking part in this study.<sup>41</sup> Although there is an obligation for local authorities to assess potentially eligible applicants, many respondents reported that local authorities were not complying with their legal duties in this respect. Many respondents only heard about the existence of Direct Payments through other people and this suggests that people who are isolated or who do not have access to knowledgeable people are likely to be disadvantaged.

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<sup>38</sup> In 2001 a figure of 2,757 payments in respect of disabled children was quoted by Davey, V. et al *Direct Payments: A National Survey of Direct Payments Policy and Practice* (PSSRU 2007).

<sup>39</sup> L Clements *Community Care and the Law* (Legal Action 2017) para 10.18.

<sup>40</sup> In which country over 83% of the respondents resided – see para 3.05 above.

<sup>41</sup> See for example Davey, V. et al *Direct Payments: A National Survey of Direct Payments Policy and Practice* (PSSRU 2007) and Blyth, C. and Gardner, A. 'We're not asking for anything special': Direct Payments and the carers of disabled children' *Disability and Society* (2007) 22(3), 235-249.

- 6.07 Even where applicants did manage to arrange for an assessment, lengthy delays that could last months or years were reported. This evidently was the cause of a great deal of stress and discomfort for many.

#### **Lack of Information and Clarity**

- 6.08 It was also concerning that a high number of people lacked basic information that would allow them to manage their budget effectively. As noted above, when asked if they were aware of the hourly rate on which their Direct Payment was calculated, 40% of those who responded were not aware of this figure. Many were also put off investigating further because of concerns that they might be seen as not able to manage effectively – an essential prerequisite for eligibility for Direct Payments. Some reported having their allowance reduced following enquiries.

#### **Restrictions on Choice and Flexibility**

- 6.09 The final issue raised – restrictions on choice and flexibility – was linked closely with our initial question about rates of pay for PAs. As shown in previous sections, almost all PAs were paid at rates near or just above the minimum wage. Although there is in theory provision for paying PAs more, particularly where specialist skills are concerned, we did not (with one exception) see evidence of this in our study. Variable rates were routinely used to pay for things such as sleep-overs and working over bank holidays, but in only one instance (relating to a BSL qualified PA – see para 5.16 above), was it reported of PAs being paid more because they needed to have additional skills. At the same time, families reported that money had been taken back by the local authority because they had not been able to spend it. The most common reason for not spending money was because families had not been able to recruit workers due to poor conditions of work.
- 6.10 Looking further at the data, it was also apparent that most local authorities did allow recipients to save up PA work hours to allow them to use them for one larger event – such as for a day out. However, many more definite restrictions had been introduced to prevent transfer of funds from one use to another. So for example, recipients who wanted to use funds to meet a need in a new way could effectively be prevented from doing so. When prevented from using funds in innovative ways, money could then be reclaimed by local authorities. Such an approach is clearly a rolling back of the principle of choice and control in relation to independent living but is likely to be an effective (but short term) way of saving money.

## **Freedom of Information request**

### **Children and adult social services**

#### **Direct payment rates under the Care Act 2014 and the Children Act 1989**

I'd be most grateful if you could supply answers to the following questions. The aim of the questions is to ascertain the standard hourly rate paid by your authority for a direct payment under the Care Act 2014 and the Children Act 1989 and the process by which this rate can be varied (if at all).

If your authority considers that complying with this request in its entirety will exceed the statutory cost of compliance limit (specified in The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004), then I ask that you respond to the following questions in the order they appear until that limit is reached.

The questions that comprise this Freedom of Information request are as follows:

1. What is the standard hourly rate paid by your local authority for a direct payment for disabled child assessed as requiring personal care support under the Children Act 1989 Part 3?
2. Is the figure stated in answer to question 1 a net figure or a gross figure? A net figure means that the council will make additional payments to cover the costs of employing the personal care worker (ie Employers National Insurance liability, employers' liability insurance costs, holiday and sickness pay etc). A gross figure means that the recipient of the direct payment must pay all the costs of employing the personal care worker from the figure stated in answer to question 1.
3. Does your council have a policy for increasing the sum specified in answer 1 above in cases where the cost of meeting the disabled child's assessed needs cannot reasonably be met by a payment at the hourly rate specified in answer to question 1?
4. If the answer to question 3 is yes, please provide a copy of that policy or explain why providing a copy of the policy is not possible.
5. What is the standard hourly rate for a direct payment for an adult in need assessed as requiring personal care support under the Care Act 2014?
6. Is the figure stated in answer to question 5 a net figure or a gross figure. The meaning of a net figure and a gross figure is the same as stated in question 2 above.
7. Does your council have a policy for increasing the sum specified in answer 5 above in cases where the cost of meeting the adults assessed needs cannot reasonably be met by a payment at the hourly rate specified in answer to question 5?
8. If the answer to question 7 is yes, please provide a copy of that policy or explain why providing a copy of the policy is not possible.

May I thank you in advance for providing the above requested information.

## Appendix 2

### Payment Rates for Direct Payments

This Appendix provides details of likely costs of employing a personal assistant. While the amounts were correct at the time of writing the report, amounts change over time and readers should check for current rates.<sup>42</sup>

#### Minimum and Living Wage

The law sets out certain employment rights for workers that apply to personal assistants. Rates of pay for PAs vary according to the age and status of workers. All employers are legally obliged to pay wages at or above the minimum wage for workers, who must be over school leaving age. At the time of writing this report there were four levels of payment, depending on circumstances. At the time of the survey (November - December 2018) the minimum wage rates were:

- £7.83 per hour – aged 25 and over
- £7.38 per hour – aged 21- 24
- £5.90 per hour – aged 18 - 20
- £4.20 per hour – aged under 18 but over compulsory school age

Payments may also be made based on the national living wage for workers over 25 and these amounts vary according to the cost of living in the areas where they work. It is important to point out that the term 'living wage' is used differently by different organisations, to indicate different amounts. The Living Wage Foundation, which first coined the term, uses it to refer to a voluntary level paid to workers over 25 that reflects the actual cost of living (in 2018 a rate of £9.00 across the UK and £10.55 in London). The UK government adopted the term living wage in 2016 to refer to a statutory level of wage paid to workers over 25. In this instance, the levels are a percentage of median earnings (currently 55% and aiming for 60%) of earnings, and lower at £7.83 in 2018.

#### On - Costs

As well as the hourly rate that a PA is paid, the employer has to consider and budget for a number of additional costs. Some of these are mandatory, such as holiday pay and national insurance contributions. Other amounts are discretionary and relate to good employment practice – for example: enhanced rates of pay for working over bank holidays. A third group are payments that need to be made if the average weekly earnings of an employee are above a certain threshold – for example: auto enrolment and pension contributions. Each of these is explained below.

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<sup>42</sup> As well as local support organisations such as Centres for Independent Living, sources of useful advice include Disability Rights UK <https://www.disabilityrightsuk.org/being-control-getting-personal-assistants-pas> and the UK Government website <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/>

## **Holiday Pay**

The employer must budget for holiday pay that is based on an entitlement of each employee of at least 5.6 weeks per annum (to a maximum of 28 days). This equates to 10.8 % of the wage bill and must be paid in addition to the cost of the salary.

## **Insurance**

The employer must also take out employers' liability insurance, an annual one off payment, which may be anything between £77 and £134 depending on the insurance company and policy they choose. As a percentage of the total amount received, this will vary depending on the size of the Direct Payment.

## **Additional Payments**

An employer would usually provide enhanced hourly rates for a PA working during a bank holiday. Although this is not mandatory it is good practice to pay at time and a half or double time rate. For double time payments, this would add approximately 2% to the costs.

The employer might consider budgeting for some retainer payment – such as half pay – if the employer went on holiday without the PA or spent time in hospital and this resulted in no work for the PA. This is again good employment practice that can help in retaining a personal assistant, rather than a requirement.

## **Travel Costs**

Consideration of travelling expenses may be necessary depending on the type of support and assistance in the particular job, and whether travelling or petrol costs are incurred as part of the work requirements.

## **Calculating Additional Costs**

Determining actual on-costs is made more complex because of the existence of thresholds for some payments. Statutory Sick Pay (SSP) of £92.05 per week is payable by the employer where a PA earns an average of least £116 per week. In some circumstances employees must be automatically enrolled in a pension and this applies if workers are aged between 22 and state pension age and earning at least £10,000 a year. In this case, the employer must pay up to 3% of the salary into the pension. Small employers can usually be exempted from Employer's National Insurance (NI) contributions. But in exceptionally big care packages this might apply, again depending upon the salary and NI deductions.

As a generalisation, the on-costs of employing a PA amount to about 23% over and above wages paid to the worker. To get an accurate figure in reality, these costs need to be worked out on an individual basis.

### Summary of likely on-costs

Travel expenses (per mile)		
Employer's contribution to national insurance if above threshold		
Holiday Pay of 5.6 weeks (assuming a 5 day working week)		10.8% of wages
Public Holiday pay (8 days at double time)		2.0% of wages
Statutory sick pay (budget for 4 weeks per annum)		2.0% of wages
Employer's Liability insurance £77.00 per annum		1.5% of wages
Pension (if the PA earns over the threshold)		3.0% of wages
Retainer costs (budget for 4 weeks per annum)		3.8% of wages

As can be seen from the above, it is not possible to make a definitive statement about amounts that are earned by a PA. The existence of various thresholds in relation to hours worked and the variation in working hours (shown in the main report) mean that amounts must be worked out individually, with a view to making best use of funds.

Nevertheless, an example is shown below, to illustrate one potential scenario. It shows the principle involved and actual rates are slightly higher.

#### **This example uses wage levels and allowances valid in 2018.**

Using the minimum wage rate for adults 25 years and over, we can make a fair estimate of the likely on - costs by applying the percentages described in this Appendix.

Paying a PA wages of £7.83 per hour, we can add 23% on top to cover on-costs. This equates to £1.80 an hour, bringing the wage rate to £9.63 per hour.

If the social service department allocated the applicant 20 hours a week, that would equate to £192.60 per week. Take home pay would amount to £156.60 per week.

### United Kingdom Homecare Association minimum pay calculation

Using similar methodology and for the same year (2018) the United Kingdom Homecare Association<sup>43</sup> calculated that the minimum hourly payment to a homecare worker would need to be £9.26 (£13.08 if National Insurance, Pension Contribution, Holiday Pay, Training Time, Sickness Pay Notice and Suspension Pay, and Mileage Payments were included). The minimum agency rate would need to be £18.01 (to cover business costs and profit / surplus).

<sup>43</sup> Colin Angel *A Minimum Price for Homecare* United Kingdom Homecare Association (2018) p.35.

## Appendix 3

### Survey Questions for Families

#### Welcome to the LEAP Direct Payment Survey

Thank you in advance for taking the time to read the following information.

Cerebra is dedicated to helping families who have a child with a brain condition. We believe that being a family is about discovering life together. That's no different for families of a child with a brain condition – except that there can be more challenges to overcome along the way. We believe the best way to overcome them is by joining families on that journey – at every step. First, we use what they tell us to inspire the world class research and innovation that Cerebra supports. Then we work with them to make the best use of the knowledge we develop so that they can go on to discover a more included, fulfilled and enjoyable life together.

#### Why are we carrying out this survey?

Cerebra's Legal Entitlements and Problem-solving (LEAP) team has identified that getting and managing Direct Payments can be a problem which can impact on the wellbeing of the child and/or his or her family. We'd like to find out more about the experiences of families in getting and managing Direct Payments and we would be grateful if you could complete this short survey. The results of the survey will be used to inform our work and enable us to better support families in the future.

#### Who can participate?

We are interested in hearing from parents/carers who:

- *are currently receiving Direct Payments; or*
- *have been offered Direct Payments but decided not to accept them; or*
- *have requested or accepted an offer of Direct Payments and the system is still being set up; or*
- *used to receive Direct Payments but decided to stop using them.*

If you require a paper copy of the survey please email Derek Tilley at [derekt@cerebra.org.uk](mailto:derekt@cerebra.org.uk) (please specify if you require larger text).

#### How long will the survey take me to complete?

We estimate the survey will take 10-15 minutes to complete.

#### Is the survey easy to complete?

Yes, all the questions are multiple choice or just require very short answers. You don't have to fill in the sections that ask for more information but if you have something to share we'd like to hear about it.

### **Will my information be confidential?**

All data collected will remain anonymous and will be kept in a database that is only accessible to those working on the survey.

### **What are the possible benefits of taking part?**

Your contribution to this research is invaluable. While you may not benefit directly by completing the survey we hope that the information you give us will help inform Cerebra's work in this area and potentially help other parents and young people in the future.

### **What do I do if I experience any problems with the survey or want to complain?**

Please email Derek Tilley at [derekt@cerebra.org.uk](mailto:derekt@cerebra.org.uk).

I have read the above and I am happy to participate. What do I do now?

Excellent! Thank you for agreeing to take part. Please click 'NEXT' below to go to the survey.

Please note: if you used to receive Direct Payments and then stopped please complete the survey as if you still receive them. Thank you.

### **1. Which of the following applies when you were told that social services agreed that you needed support services?**

- The local authority offered us Direct Payments for some/all of the support needs and we accepted
- The local authority offered us Direct Payments for some/all of the support needs but we turned the offer down
- The local authority didn't offer Direct Payments but we requested them for some/all of the support needs and they agreed
- The local authority didn't offer Direct Payments but we requested them for some/all of the support needs: however, they refused our request so we don't receive Direct Payments (please explain briefly the reasons they gave in the box below)
- I didn't know about Direct Payments and the local authority didn't inform me about them

Please add any comments you'd like to make

### **2. Why did you decide not to have Direct Payments? (Please tick all the boxes that apply - you can tick more than one box)**

- I didn't want to take on the role of managing Direct Payments

- The amount offered as Direct Payment was insufficient
- I couldn't find suitable support staff

Please provide any additional information that you think is appropriate

**3. Does your local authority offer a managed account service? (This is where the local authority, or another organisation funded by the local authority, pays your staff or the agency you use and deals with things like tax and national insurance on your behalf.)**

- Yes and we use, or will use, the managed account service
- Yes but we don't, or won't, use the managed account service
- No
- Don't know

Please provide any additional information that you think is appropriate

**4. Are there charges for using the managed account system?**

- Yes (Please explain briefly below what the charges are for and how much is charged)
- No

Please add any comments you'd like to make

**5. Do you know the hourly rate (or rates) on which the local authority calculate your Direct Payment?**

- Yes
- No
- Don't know

**6. If yes, what is the hourly Direct Payment rate? Some authorities pay one rate if you use an agency (e.g. a registered care provider) and another if you employ a personal assistant yourself. If you use an agency and employ a personal assistant and you know what these rates are please give both. Otherwise, simply give the one you are paid.**

**7. Does the hourly rate paid by your local authority include such items as national insurance, holiday pay, sick pay and employer's liability insurance?**

- Yes
- No

Please add any comments you'd like to make

**8. How much do you, or will you, receive in Direct Payments per month in total? (If you don't know the figure, what do the Direct Payments pay for? – e.g. 4 hours of PA support during school term time and 8 hours during the school holiday)**

**9. How do you, or will you, spend the Direct Payments? (Please tick all the boxes that apply to you – you can tick more than one box)**

- Employing one or more personal assistant

- Paying for an agency
- Paying for services direct

Other (please specify)

**10. What are the things that work well, or you think will work well, in setting up and managing Direct Payments? (Please tick all the boxes that apply to you - you can tick more than one box)**

- Flexibility
- We're in control
- We can find personal assistants with the necessary skills
- We can pay the agency of our choice
- Reliability of personal assistants
- It is easy to deal with short term problems - for example, finding suitably qualified cover during staff holidays or periods of sickness
- None of the above (Please give brief details in the box below)

Please add any comments you'd like to make

**11. Do you think that the amount of Direct Payments awarded is sufficient to cover all of the needs that have been identified by social services?**

- Yes
- No,

Please add any comments you'd like to make

**12. Do you think that the hourly rate of Direct Payments is sufficient?**

- Yes
- No, it's not enough to attract suitably trained staff
- No, it's not enough to retain suitably trained staff
- Not always
- Other

Please add any comments you'd like to make

**13. Have you experienced difficulties getting the local authority to agree to pay for associated costs such as essential training for personal assistants, necessary travel or other expenses incurred to meet the identified needs?**

- Yes
- No

Please add any comments you'd like to make

**14. Are you still in the process of setting up Direct Payments?**

- Yes
- No

**15. Do you sometimes have trouble spending all of the allocated Direct Payments?**

- Yes (Please explain briefly why in the box below)
- No

Please provide any additional information that you think is relevant

**16. If you sometimes have trouble spending all of the allocated Direct Payments:**

- Are you allowed to keep it and spend it later on identified needs? (e.g the personal assistant is ill for three weeks and you can't find suitable cover; you then use the unspent money to pay for extra personal assistant support during the next summer holiday)
- Does the local authority take it back?

Other (please specify)

**17. Are you allowed to 'bank'/accumulate hours? This is where, for example, you are allocated 2 hours of personal assistant support per week but do not use them for 3 weeks and then use them to enable your child to have a day trip.**

- Yes
- No

**18. Have you had your Direct Payments support package cut since it was set up?**

- Yes
- No

Please explain briefly the reason you were given for the cut

**19. Have you previously had a Direct Payment and then decided not to continue with it?**

- Yes (Please briefly explain why in the box below)
- No

Please add any comments you'd like to make

**20. In which local authority do you live? (This is who you pay your council tax to) (Please leave blank if you'd rather not say)**

**21. How old is your child?**

**22. That's all the questions we have for you but please feel free to add any comments you may have about getting and managing Direct Payments in the box below**

**The LEAP Team would like to say a big thank you for taking part in our survey**

## Appendix 4

### List of Authorities featuring in the family survey responses

1. Angus
2. Bath and North East Somerset x 2
3. Bexley LBC x 3
4. Blackburn with Darwen MBC
5. Blackpool
6. Barnsley
7. Boston Borough Council
8. Bridgend x 6
9. Bristol x 4
10. Buckinghamshire
11. Calderdale x 3
12. Cardiff x 2
13. Carmarthenshire
14. Ceredigion x 2
15. Cheshire East x 2
16. Cornwall x 7
17. Coventry x 7
18. Croydon x 13
19. Cumbria x 3
20. Cheshire West and Cheshire x 2
21. Derby x 2
22. Derbyshire
23. Devon x 5
24. Dorset x 2
25. Dumfries
26. Ealing in London.
27. East Sussex x 2
28. East Yorkshire
29. Eastbourne
30. Dorset
31. Exeter
32. Gloucestershire x 3
33. Greenwich x 2
34. Hampshire x 4
35. Hertfordshire x 4
36. Highland x 2
37. Hillingdon LBC
38. Horsham
39. Isle of Anglesey
40. Kent x 3
41. Kirklees x 2
42. Lancashire
43. Leeds x 5
44. Leicester
45. Lincolnshire
46. Liverpool x 2
47. Sutton LBC
48. Waltham Forest LBC x 3
49. Manchester City Council x 2
50. Merthyr Tydfil CBC.
51. Merton LBC
52. Mid Sussex
53. Milton Keynes
54. Monmouthshire x 4
55. N Somerset
56. Neath Port Talbot CBC
57. Newport (Wales)
58. South Eastern Health and Social Care Trust (Northern Ireland).
59. North East Lincolnshire
60. North Somerset x 2
61. North Yorkshire x 4
62. Northampton
63. Northern Ireland
64. Northumberland
65. Nottinghamshire
66. Oxfordshire
67. Plymouth
68. Reading Borough Council x 3
69. Rhondda Cynon Taff
70. Scottish Borders Council x 2
71. Sedgemoor x 2
72. Sefton x 2
73. Sheffield x 6
74. Solihull x 3
75. Somerset x 2
76. South Gloucestershire
77. South Northamptonshire x 5

78. South Ribble
79. St Helens x 7
80. Staffordshire County x 2
81. Stockton on Tees
82. Surrey x 3
83. Swansea x 4
84. Swindon
85. Thurrock
86. Torbay
87. Vale of Glamorgan x 2
88. Wakefield
89. Warrington x 3
90. Warwickshire x 3
91. West Devon
92. West Lothian
93. West Sussex x 2
94. Wirral