

Independence, Choice and Control

DLA and personal mobility in state-funded residential care

Volume 1: Report

Oral and written evidence is contained in

*Volume 2 available on the Low Review website at
www.lowreview.org.uk.*

1. Notes

1.1 Terms used in the report

Residential care

Residential care refers to long-term care given to adults or children in a residential setting rather than in their own or family home. The Review has focused on those living in state-funded residential care, as opposed to those who fund their own care. Individuals living in state-funded residential care are generally required to contribute any income they receive to help meet the costs of care. The only income that many people are able to keep is a small Personal Expenses Allowance of just over £20 per week and the mobility component of Disability Living Allowance. In some cases this can be a similar level of contribution to self-funders who, once they have financed their care, often using benefits as well as other income, can be left with little remaining finance.

The Review has not included supported living.¹

Residential schools and colleges

Care or learning needs may mean that young disabled people need to attend a residential school or college, staying away from their family home.

Personal mobility

Personal mobility is the ability to get around. People can face additional costs associated with mobility because of their disability. For example, someone may need to purchase a mobility aid or they may need to pay for things like accessible transport. Some people may not be able to travel independently or are unable to drive because of their disability and are therefore reliant on others for their transport needs.

Disability Living Allowance

Disability Living Allowance (DLA) provides support with the extra costs experienced by disabled people. It is paid in two components: the care component and the mobility component. The care component stops after 28 days when someone moves into state-funded residential care but they continue to be eligible for the mobility component. Both the care and mobility components stop after 28 days if someone is in hospital, unless self-funding. The mobility component of DLA is sometimes referred to as 'DLA mobility' in this report.

Personal Independence Payment

¹ The policy proposal to no longer pay the mobility component of Disability Living Allowance (DLA) to disabled people living in state-funded residential care, does not apply to those in a supported living setting or those who are self-funding their own care.

Personal Independence Payment (PIP) is due to replace DLA. From March 2013 everyone between 16 and 64 currently receiving DLA will be assessed for PIP and, if eligible, people currently receiving the mobility component of DLA will instead receive the mobility component of PIP.

1.2 Quotations used in the report

- Unless otherwise indicated, quotes appearing in this report are from disabled people living in residential care.
- Personal stories appearing in the text may have been shortened but the words used are those of individuals relating their experiences.

1.3 Territorial extent of the report

The Review and the concluding report apply to England, Scotland and Wales. The proposed change to the mobility component would apply only to Great Britain.

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3. Foreword

By Lord Low of Dalston

The Government's proposal to withdraw the mobility component of DLA from disabled people in state-funded residential care has touched a nerve with the disability community. The issue is seen as iconic - a touchstone of the extent to which public policy is in sympathy with the sensibilities and aspirations of disabled people. The Government is undertaking its own review, but I was pleased to be asked by Mencap and Leonard Cheshire Disability to lead this more public review of the funding of mobility for disabled people in state-funded residential care. We have endeavoured to be as open and transparent as possible, and I hope our report will help the Government to come to the right conclusion.

Our call for evidence met with a good response. I am immensely grateful to all those who took the time and trouble to give us evidence, both written and oral; to the members of the Steering Group who worked with me; and to our hard-working secretariat from Mencap and Leonard Cheshire Disability.

What came across to us most forcibly from the evidence we received was that the mobility component is so valued by disabled people because of the independence, choice and control it enables. It helps disabled people to take charge of their lives as individuals instead of being dealt with impersonally as a group. As one witness said to us, "DLA makes the difference between existing and having a life that's worth living".

For those living in residential care, the need for mobility is the same as everyone else's. There is a broad spectrum of need whether one lives in the community or in residential care. It was put to us that the proposal to withdraw the mobility component from those living in residential care exemplifies an outmoded conception of residential care which puts it on a par with being in hospital. It could even be argued that to withdraw the mobility component from those living in residential care would discriminate against them as compared to those living in the community. It certainly does not sit easily with the Government's personalisation agenda.

Mobility underpins the exercise of many of the rights contained in the UN Convention on the Rights of Persons with Disabilities, for example, to education, employment and to participate in social, cultural and political life. Withdrawing the mobility component from those living in residential care risks marring the good account which the Government would otherwise wish to give the UN monitoring committee of its compliance with the Convention.

These are just some of the considerations, expanded on in our report, which we believe the Government needs to take into account in coming to a final conclusion on whether to withdraw the mobility component from those living in

state-funded residential care. But regardless of that, our report contains recommendations for bringing greater clarity to the funding of disabled people's mobility needs more generally, and regulating the use of people's DLA mobility component by care home providers which we hope the Government will find helpful in giving greater transparency and coherence to the system of mobility funding for disabled people, their families and carers.

C. M. Low

Colin Low

4. Executive Summary

“...people in residential care should have the same entitlement as anyone else to exercise choice and control over their care and how they live.” A Vision for Adult Social Care²

4.1 Introduction

The 2010 Spending Review included plans to end payment of the mobility component of Disability Living Allowance (DLA), soon to become Personal Independence Payment (PIP), to people living in state-funded residential care. As a consequence, the Welfare Reform Bill currently before parliament contains the power to end these payments.

There has been widespread concern about the impact that removing this benefit would have. In February, the Government announced plans to conduct an internal review into the measure. However, concerns that the Government's review was taking place behind closed doors prompted Mencap and Leonard Cheshire Disability to ask Lord Low of Dalston to conduct an independent, public review into personal mobility in residential care. The Low Review was launched in July 2011 with a call for written evidence. It has received over 800 submissions from individuals, local authorities and providers, and held six oral evidence sessions.

4.2 The Review

The Review set out to produce an independent report focusing on:

- how the mobility component of DLA is being used by care home residents and the impact of the loss of this benefit;
- funding arrangements for meeting personal mobility needs between local authorities and care home providers;
- responsibilities of care home providers in relation to the mobility needs of residents.

4.3 Findings

The Review began by asking disabled people what their mobility needs are. The clear and simple answer was that their needs are the same as non-disabled people. Many disabled people do, however, face additional costs or require support in meeting those needs. The Review found that a diverse range of support can be required, including adapted vehicles, specialist wheelchairs or assistance from another person.

Many different reasons have been put forward by the Government for the proposed removal of the mobility component from people living in state-funded residential care – in particular, that there is an overlap between local authority funding and DLA mobility, and that personal mobility is the responsibility of

² *A Vision for Adult Social Care: Capable Communities and Active Citizens*, Department of Health, November 2010: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508

providers of residential care. DLA mobility, local authorities and providers all play a part in meeting mobility needs; the Review therefore examined each of these in turn.

The Review found that DLA mobility is key to meeting the *personal* mobility needs of care home residents. The evidence received by the Review overwhelmingly shows that DLA offers personalised support and provides the individual with choice and control over how their mobility needs are met. The Review did find some instances where the benefit was being used in a way that might not be considered appropriate, but these were exceptions. However, where there are issues with the use of DLA mobility – for example where individuals are not being given the freedom to spend their DLA mobility as they choose – this should clearly be addressed. The Review felt that this could be done within the existing system, with appropriate guidance, and found no evidence that would justify withdrawing the benefit.

The responses received from local authorities showed that, in general, the support provided by local authorities was aimed at meeting a different category of mobility need from those supported by DLA mobility. Local authority funding for mobility focused on the support needed to meet assessed care needs, for example travel to a day service, rather than a personal need like visiting friends and family. There was therefore no overlap between the support provided by DLA mobility and that offered by local authorities. In a small number of cases, local authority responses implied that DLA mobility was taken into consideration as a means of meeting mobility needs related to the provision of social care, rather than being left to meet those personal mobility needs for which it is intended. The lack of consistency over responsibility for mobility in local authority responses shows the need for clear guidance to local authorities when it comes to funding mobility needs and the role played by DLA mobility.

When asked about their role in meeting mobility needs, providers of residential services were clear that they were not usually funded to meet personal mobility needs. In many cases, providers stated that mobility needs were not specified at all in contractual arrangements with local authorities. However, providers commonly stated that they were contracted to provide for day-to-day mobility needs where these were associated with an individual's assessed care needs. There were some instances of services requiring residents to use their DLA mobility in a certain way. It is important that this is addressed by ensuring that any collective use of DLA mobility is on a purely voluntary basis. The role of providers is to deliver their contractual obligations in relation to the mobility needs identified by the local authority, with DLA mobility existing alongside this to meet those more individualised and personal mobility needs of residents.

Underpinning all of these findings is the importance of mobility to disabled people's rights. It is mobility that enables people to participate in their community, gain an education, maintain a family life or work. Allied to this is the importance

of choice and control. Disabled people must have control over how they exercise their rights. Ending payment of the mobility component to people living in residential care would deny people control over their own lives and undermine the Government's own commitment to greater personalisation in the support provided to disabled people.

4.4 Conclusion

The Review found no evidence of overlap in the support offered by the mobility component of DLA and that offered by local authorities and providers, all of which play a distinct part in meeting disabled people's mobility needs. Whilst action needs to be taken to ensure local authorities are performing their duties and that residential services are adequately funded to provide the mobility support necessary to meeting assessed needs, it is DLA mobility that provides the most appropriate means of meeting personal mobility needs. If the rights of disabled people are to be preserved then it is vital that DLA mobility, and its successor under PIP, are retained for people living in residential care.

5. Introduction

5.1 The proposed removal of DLA mobility from people living in state-funded residential care

The 2010 Spending Review announced Government plans to cease paying the mobility component of Disability Living Allowance (DLA) to disabled people living in state-funded residential care from October 2012. This was later pushed back to March 2013 to coincide with the introduction of Personal Independence Payment (PIP) which is due to replace DLA.

From March 2013 everyone between 16 and 64 currently receiving DLA will be assessed for PIP and, if eligible, people currently receiving the mobility component of DLA will instead receive the mobility component of PIP. The Review has therefore focused on working age recipients.

5.2 The role of the Low Review

The Government has been conducting an internal review into how personal mobility needs are met and funded in state-funded residential care. Disability organisations concerned about the removal of the mobility component of DLA from people living in residential care, felt it was important that disabled people had the opportunity to express their views and that there was a more public debate on the issue. Mencap and Leonard Cheshire Disability therefore asked Lord Low of Dalston to chair an independent review into personal mobility in relation to disabled people living in residential care. The Low Review is intended to run in parallel with and complement the Government's review by providing an opportunity for public contributions.

The Review set out to produce an independent report focusing on:

- how the mobility component of Disability Living Allowance (DLA) is being used by care home residents and the impact of the loss of this benefit;
- funding arrangements for meeting personal mobility needs between local authorities and care home providers;
- responsibilities of care home providers in relation to the mobility needs of residents.

The full terms of reference for the Review are included in Appendix 1.

The Review was chaired by Lord Low of Dalston, Vice-President of the Royal National Institute of Blind People (RNIB) and President of the Disability Alliance.

Lord Low was supported by a steering group with a range of relevant expertise: Wendy Tiffin, a recipient of DLA mobility and a care home resident; John Adams OBE, General Secretary of the Voluntary Organisations Disability Group (VODG); Pauline Bardon, mother of a disabled teenager; Judith Geddes, Co-Chair of the Resources Network for The Association of Directors of Adult Social Services (ADASS); Dr Peter Kenway, Director of the New Policy Institute;

and Gary Vaux, Chair of the Social Security Advisers Group at the Local Government Association (LGA).

5.3 The report

This report begins by looking at disabled people's mobility needs and proceeds to examine the different support available for meeting these.

Disabled people have a wide range of different mobility needs (Chapter 7). The mobility component of Disability Living Allowance (DLA) provides the most personalised means of meeting these needs (Chapter 8). Other support comes from local authorities who pay to meet some of the mobility related to the provision of social care (Chapter 9), but this fails to offer the choice and control, or the support in meeting personal needs, provided by DLA mobility. Providers of residential care seek to support the mobility needs of residents (Chapter 10), but rely on external funding, either from local authorities or DLA mobility, to do this. The position of young disabled people attending residential schools and colleges (Chapter 11) is broadly similar to that of adults living in residential care, with some needs met by their school or college, but DLA mobility playing a vital part in ensuring independence.

Underpinning the issue of personal mobility for disabled people are those rights enshrined in the UN Convention on the Rights of Persons with Disabilities (Chapter 12), although in general the emphasis is on mobility as a means of realising other rights.

6. Methodology

The Review adopted a three-stranded methodology for gathering evidence, comprising:

- A literature review of relevant legislation and publications;
- Distribution of a formal call for written evidence;
- Oral evidence sessions.

6.1 A review of relevant legislation and publications

The secretariat reviewed:

- Relevant legislation, including the Welfare Reform Bill currently before Parliament;
- Social care legislation and guidance as it relates to personal mobility and residential care;
- Previous reports on the proposed removal of the mobility component from people living in residential care;³
- Parliamentary questions and debates on the proposed removal of the mobility component from people living in residential care.

6.2 Written submissions to the review

A 12 week consultation period was given for written submissions. The consultation began with a formal call for evidence on 18th July 2011 and closed at midnight on 10th October 2011.

Submissions were invited from anyone with an interest, particularly people living in state-funded residential care, Disabled People's Organisations (DPOs), care home providers and local authorities. Responses could be submitted by post, email, via an online survey, or by telephone. An easy read version of the call for evidence was also published.

The call for evidence and online questionnaire contained a series of questions for local authorities, providers and individuals. Submissions could be made anonymously. Any material that could be attributed to individuals or allow them to be identified would be anonymised before publication.

The Review also welcomed submissions of supporting evidence, such as copies of community care assessments or plans (provided personal data had been removed) and service level agreements between local authorities and care home providers.

³ See: *Don't Limit Mobility*, January 2011, and *DLA Mobility: Sorting the facts from the fiction*, March 2011: www.disabilityalliance.org/dbc3.htm

Also see: *How am I going to put flowers on my dad's grave: Care home residents' use of the mobility element of the Disability Living Allowance*, May 2011: www.capability-scotland.org.uk/news-events/latest-news/scdr-research/

A total of 828 written submissions were received: 652 from individuals (557 questionnaires, 95 unstructured),⁴ 130 from care home providers (93 questionnaires, 37 unstructured), and 46 from local authorities (all questionnaires).

Although the primary focus of the Review was in relation to residents of care homes, the call for evidence was extended in order to consider young disabled people aged 16 or over attending a residential school or college. This had far fewer responses with a total of 10 submissions from individuals and 2 submissions from young people's charities. Although they were asked to contribute, no residential school or college provided a formal written submission; this is likely due to the shortened consultation period for the schools and colleges call for evidence.

All written submissions were analysed by the Review secretariat and an independent researcher.

6.3 Oral submissions to the Review

Invitees to submit oral evidence were chosen by the steering group to represent the following groups:

- Individuals with direct experience of receiving mobility support in residential care
- Disabled People's Organisations
- Local authorities and devolved administrations
- Government representatives
- Charities
- Providers of residential care
- Motability
- Special school/college providers
- Academic experts

Not everyone invited to present oral evidence was able to attend. Appendix 2 includes a full list of those who did provide oral evidence.

The steering group are grateful to everyone who took part in the call for evidence. In particular the steering group would like to thank all those who shared their personal experience of mobility in residential care, especially those people who welcomed us into their homes.

⁴ Responses to the individuals call for evidence included some representations from organisations and bodies such as Learning Disability Partnership Boards (LDPBs); additionally the Review received 17 'unstructured' submissions from disability charities and Disabled People's Organisations (DPOs).

7. Disabled people's mobility needs

Overview

Disabled people have the same need for mobility as everyone else. Mobility is about the ability to get around: everyone has mobility and transport needs. However, for disabled people there may be additional costs, adaptations and support required in meeting these needs compared to non-disabled people. Support must focus on enabling disabled people to enjoy personal mobility in the same manner as non-disabled people.

“The mobility needs for disabled people...is almost the same as mobility needs for anyone...in order to get around, to be able to partake, not just in work, but also in a social life, to make sure that someone who has a disability is not disadvantaged by the fact that...they can't perhaps take public transport... So, by its very nature, people [with] mobility problems do spend a lot more...than those who don't have mobility problems.” Dame Anne Begg MP

7.1 What disabled people need support to do

The Review asked people completing the call for evidence what activities they need mobility support to take part in. It emerged that disabled people have the same mobility needs as everyone else. The long list we were given included visiting the GP, visiting family and friends, participating in local groups, shopping, getting one's hair cut, going to the cinema, going to the pub and going fishing.

7.2 The type of support people need

The Review asked people about the sorts of mobility support they needed:

Taxis

Accessible taxis can be the only alternative when local public transport is not accessible. However, particularly outside of major cities, there can be limited availability and they can cost more than non-accessible taxis.

Public transport

When driving is not possible then disabled people often rely on public transport to a greater extent than non-disabled people. Whilst accessibility is improving, not all services are accessible, the distance to a bus stop or station can make using public transport impractical and there are often limited accessible spaces for wheelchair users.⁵

Service transport

Most residential services have some form of service transport. This is often either a number of adapted cars or an accessible minibus. Evidence received shows

⁵ This view is reflected in the report commissioned by Capability Scotland and Margaret Blackwood Housing Association by the University of Glasgow: *How am I going to put flowers on my dad's grave?* From interviews with over 50 care home residents public transport was found to be inaccessible to the majority.

that many services charge a fee for using this transport for personal use, often paid for out of an individual's DLA mobility.

Adapted car

Adapted cars may be driven by the individual or adapted to enable them to travel as a passenger.

Manual mobility aid

Manual mobility aids include equipment such as walking frames, manual wheelchairs and easy chairs.

Powered wheelchair

Powered wheelchairs can offer greater mobility than traditional manual wheelchairs, enabling people to travel greater distances with less assistance.

Support worker

Support workers can provide a range of different forms of practical mobility assistance.

Respondents to the call for evidence particularly stressed the importance of taxis, service transport, adapted cars and support workers. It was also clear that individuals generally use a range of different support options, for example a powered wheelchair and taxis. These support needs apply regardless of whether someone lives in their own home or a residential service.

7.3 How needs change according to where you live

Disabled people living in residential care can also face additional mobility costs due to the rural or suburban location of many residential services. Whilst public transport in major cities has limited accessibility, in rural areas there often isn't any accessible option.

“What is unfair, I would love to be able to use local transport but we don't have buses that go to the town which are able to take wheelchairs.”

“I live in a rural home and have used taxis to access the local town at a cost of £30 each way.”

As a recent report by Scope emphasised, it is important that when assessing disabled people's needs, the social model of disability is applied, and that those wider environmental factors that can prove disabling are taken into consideration, rather than focusing solely on an individual's impairment.⁶

⁶ *The future of PIP: a social model based approach*, Scope et al, October 2011:
www.scope.org.uk/campaigns/publications/future-pip

7.4 Individual views of mobility funding

The call for evidence asked individuals how their mobility needs were funded. The most common response was DLA mobility. This enabled people to attend medical appointments (43%), go shopping (63%), meet friends (64%) and family members (60%), and attend local groups and clubs (62%), amongst other things.

Very few people cited the local authority as funding their mobility needs. Where the local authority was identified, the highest figure, just 16%, was in relation to mobility support to attend a day service. The inference, which reflects later observations in this report, is a tendency for local authorities only to fund mobility costs where they relate to meeting an assessed (social care) need. People were more likely to cite their residential service as meeting their mobility needs than their local authority. However, given almost 40% of respondents were unaware of, or had not seen a copy of, their community care plan or assessment, it is difficult to determine whether people were always clear as to the distinction between what was funded by their local authority and what was provided additionally by their residential service.⁷

It was noticeable that private income or funding from families played a large role, particularly when it came to visiting family. Respondents noted that private income or funding from their family covered activities like the cost of family visits, meeting friends and going out to a range of social engagements. Given the individuals' call for evidence was targeted at people living in state-funded residential care, in most cases it is unlikely respondents have significant private income as means testing rules leave most people with only their DLA mobility and £22.60 per week Personal Expenses Allowance⁸. Responses to this question therefore indicate a heavy reliance on support from friends or relatives in meeting mobility costs, with this group generally seen as a greater source of support than local authorities and residential services. This reliance on private or family support is an indicator that individuals are already receiving too low a level of mobility support to fully meet their needs.

7.5 Key findings

- Disabled people have a diverse range of mobility needs.
- People need mobility support in order to participate in a wide range of activities.
- DLA mobility is the most important source of support in meeting mobility needs.
- Family and friends also provide support with mobility needs.
- Disabled people generally feel that local authorities and providers play a relatively small role in meeting their mobility needs.

⁷ This contradicts recommendation 30 of the Law Commission report into adult social care, which states that the statute should place a duty on a local authority to ensure the production of a care and support plan for people with eligible assessed needs. Recommendation 32 also includes that care and support plan regulations must specify that a copy of the plan be made available to the service user. See: www.justice.gov.uk/lawcommission/publications/1460.htm

⁸ As at October 2011; the Personal Expenses Allowance (PEA) is provided to care home residents and can be spent as the individual sees fit on personal items, such as clothes, social activities and gifts.

8. How Disability Living Allowance meets mobility needs

“If my mobility were stopped I would be a prisoner within my home, without this help I wouldn’t be able to get out to see family, go for appointments, or socialise with my friends. My independence would be non-existent.”

Overview

Disability Living Allowance (DLA) provides support with the extra costs experienced by disabled people as a result of their disability or condition. Witnesses and respondents commonly focused on the flexibility and freedom that DLA gives disabled people to make their own choices. It was noted that the removal of the mobility component of DLA would result in a loss of independence for disabled people who happen to live in residential care and be a ‘step backwards’ for disabled people’s rights.

Disability Living Allowance (DLA) is designed to meet the extra costs associated with disability. It is paid in two components, the care component and the mobility component. The care component is aimed at helping offset some of the costs disabled people experience in their daily life, whilst the mobility component is aimed at helping meet additional mobility costs. The care component stops when someone moves into state-funded residential care but they continue to be eligible for the mobility component. DLA was intended to provide more personalised support, giving individuals greater control over how their needs are met.

The mobility component is paid at two different rates. For 2011/12 the lower rate is £19.55 per week and the higher rate is £51.40 per week.

The Disability Living Allowance and Disability Working Allowance Act 1991 inserted the following criteria into the Social Security Act 1975:

37ZC.- (1) Subject to the provisions of this Act, a person shall be entitled to the mobility component of a disability living allowance for any period in which he is over the age of 5 and throughout which-

- (a) he is suffering from physical disablement such that he is either unable to walk or virtually unable to do so; or
- (b) he falls within subsection (2) below; or
- (c) he falls within subsection (3) below; or
- (d) he is able to walk but is so severely disabled physically or mentally that, disregarding any ability he may have to use routes which are familiar to him on his own, he cannot take advantage of the faculty out of doors without guidance or supervision from another person most of the time.

(2) A person falls within this subsection if –

- (a) he is both blind and deaf; and
- (b) he satisfies such other conditions as may be prescribed.

(3) A person falls within this subsection if –
(a) he is severely mentally impaired; and
(b) he displays severe behavioural problems; and
(c) he satisfies both the conditions mentioned in Section 37ZB(1)(b) and (c) above.

...

(11) The weekly rate of the mobility component payable to a person for each week in the period for which he is awarded that component shall be –

(a) the higher rate if ... being likely to satisfy one or other of the conditions mentioned in subsection 1 (a), (b) and (c) above...

(b) the lower rate in any other Case.

8.1 The future of DLA

The Government has announced that it plans to replace DLA with a new benefit called Personal Independence Payment (PIP), and from 2013 everyone currently receiving DLA between the ages of 16 and 64 will be reassessed for the new benefit. Like DLA, PIP will aim to meet the extra costs experienced by disabled people as a result of their impairment. PIP will also be paid in two components, daily living and mobility, although no information is available yet as to the rate at which these will be paid. As part of these changes the Government proposes to stop paying the mobility component to people living in state-funded residential care. The Welfare Reform Bill currently before parliament provides the power to do this.

8.2 The impact of removing DLA mobility

When asked about the impact the proposed removal of the mobility component would have, witnesses and respondents were clear that it would result in a significant loss of independence for disabled people.

“If I don’t get mobility money, I will feel that I am stuck indoors with nothing to do or see. It will make me feel lonely, depressed and like I can’t live my life like I want to...It gives me my independence to live my life as a person even though I have a disability.”

“It’s very hard to see how this proposal is going to do anything other than directly compromise the ability of disabled people to live independent lives.” Ruth Scott, Scope

It was felt that removing mobility payments would be a step backwards for disabled people’s rights.

“Can you imagine being stuck at home all day every day with very little access to the outside world and the stimulation that this brings? This is a world from which we had progressed and not one, as a civilised society, we should return to.”

“I think this issue has become sort of emblematic for disability groups and organisations...we don’t want to turn the clock back.” Liz Sayce, Radar

8.3 Attitudes to disabled people living in residential care

Concerns were raised that the proposal to remove DLA mobility was based on a misconception of people living in residential care, with disabled people viewed as ‘too ill’ or ‘too disabled’ to be able to, or to want to, participate in society in the same way as non-disabled people. At the time of announcing plans to remove DLA mobility, references were made to people in residential care being in a comparable position to hospital in-patients⁹ and there was an implication that people would be able to share transport.

“...I think that some parts of government must have quite old-fashioned ideas about what residential care is and what it does and the kind of people who are in residential care, [they] must think that they want to lead very limited lives.” Sue Bott, NCIL

8.4 DLA mobility in relation to health and wellbeing

Witnesses and respondents talked about the impact on the health and wellbeing of individuals if mobility support were to be reduced. In particular they focused on the impact on mental health if people were unable to participate in life outside of the residential home due to a lack of mobility support.

“I need to use a wheelchair at all times as this is my only way of getting around. If I don’t have the money, I won’t be able to go out. So I will become isolated, lonely, get depressed...”

“I would like to emphasise...the linkage between having mobility and the health and wellbeing of the residents in care homes or indeed residential colleges...If we don’t enable people in care homes to have what one could call ordinary lives, to be able to maintain contact with family and community, to engage in healthy activities, thinking of the government’s health and wellbeing board, there is a risk of a drift to a nursing home...the health and wellbeing issue is very important.” Dame Philippa Russell, Standing Commission on Carers

8.5 The personalised support offered by DLA mobility

Respondents focused heavily on the personalised nature of DLA. In contrast to social care, where funding is prescribed to meet specific needs, DLA provides much greater flexibility.

“...what DLA offers is that freedom and that flexibility to enable disabled people to design their own life and make their own choices...DLA is a

⁹ Prime Minister’s Question Time, 12th January 2011:
www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110112/debtext/110112-0001.htm

hugely symbolic benefit. It's an incredibly progressive idea." Ruth Scott, Scope

"...independent, flexible mobility is absolutely vital, and I have no doubt whatsoever that the mobility component of DLA has made a huge difference. It has actually transformed lives... It is a personal budget for mobility." Dame Philippa Russell, Standing Commission on Carers

"By removing the mobility component of DLA from our daughter and son that is precisely what you will be doing: restricting, diminishing indeed, their choice and control over the manner in which they can best live their lives."

If the mobility component were to be removed from people living in residential care, this personalised support and the independence that comes with it would be lost. It would also risk creating a two tier system, where people receiving care in their own home or self-funding a residential care placement would be able to keep their DLA mobility, and have greater choice and control than people living in state-funded residential care.

Recommendation 1:

As Personal Independence Payment is introduced, disabled people living in state-funded residential care should be eligible to receive the mobility component on the same basis as disabled people receiving care in their own home.

8.6 Who controls individuals' DLA mobility?

The Review asked individuals responding to the call for written evidence who manages their DLA. 41% said that they managed it themselves but 53% said that either a relative or the residential service managed their payments. The Review then asked if this was a formal or informal relationship. In 97 cases it was described as a formal relationship, and in 38 cases it was described as an informal relationship.

The move towards increasing personalisation in residential care places the individual at the centre of all decisions about how their needs are met. Therefore, consideration should be given to whether it is appropriate for someone not formally accountable through a recognised mechanism, such as an appointeeship, to have control of an individual's mobility payments.¹⁰

The goal should be for more people living in residential care to have direct control over their mobility component. In line with the move towards greater

¹⁰ If a person is entitled to benefits (including DLA) and has no other money from elsewhere, the DWP can appoint an 'appointee' to act on their behalf if they cannot act for themselves. This is usually a relative or friend but can also be a 'body' of people, for example, a housing association. Payments are paid to the appointee who must spend them in the best interests of the claimant. If they have any other money (for example savings or other income) then they will need a bank account and a financial deputy to be appointed to manage their bank account for them.

personalisation, more work needs to be done to empower individuals to manage their benefit payments.

Recommendation 2:

The Department of Health should develop a peer led initiative encouraging and supporting people living in residential care to directly manage their Personal Independence Payment mobility component. Equivalent action should be taken in Scotland and Wales.

8.7 Motability

Many people lease adapted cars through the Motability scheme. The Review asked respondents to the written call for evidence if they had a Motability vehicle and if so where it was kept.

Motability

Motability is a scheme that enables disabled people and their families to lease adapted cars using their DLA mobility. Anyone aged over three and in receipt of either the higher rate of DLA mobility component or the War Pensioners' Mobility Supplement, and expected to keep receiving this for at least another year, is eligible for the scheme. Cars are leased for a period of 3 or 5 years and an individual's mobility payment goes directly to Motability during that period to cover the cost of the vehicle. The Motability scheme also covers insurance, servicing and car tax.

Who uses Motability?

Of those responding to the individuals' call for evidence, 90 said they had a Motability car and 83 of these said this was kept with a relative. In most cases respondents were clear that relatives used the Motability car to meet the mobility needs of the individual living in residential care. Witnesses presenting oral evidence were asked whether they were aware of vehicles being misused (for example, an individual's family member having primary or even exclusive use of the vehicle) and the general response was that people were aware of isolated instances but that this was not widespread.

"...the student is actually with us 52 weeks of the year... so I've already had the debate with the parents. When are you going to give this [DLA mobility] up for your daughter because actually it's her money?" Anne Price, NATSPEC

"I have a wheelchair accessible vehicle. My wife and daughter use it to drive me about and to visit me. It is kept at my family home. Without it I could not go home on Sundays, or go to my children's concerts, or go shopping, or meet up with friends. I would be imprisoned in my nursing home."

Whilst a large number of respondents cited a relative as keeping the Motability car at their home, very few people talked about misuse. Therefore the Review feels it is important that work be undertaken to examine the reasons why Motability cars are potentially kept with relatives and any barriers to keeping the vehicle with the individual living at the residential service. For example, one respondent talked about the lack of staff at the residential service able to drive the Motability vehicle. The Review felt that there were wider issues to consider, such as the availability of parking spaces and the cost of insuring multiple drivers.

“We have insured the vehicle for any driver over the age of 25 but the residential setting where he lives only has one person who fulfils this criteria as most staff are from overseas and do not have a full drivers license.”

The Review believes it is important that this work is carried out before any restrictions on the use and keeping of Motability vehicles are introduced, including the recently announced requirement that all nominated drivers live within five miles of the individual in receipt of the Motability vehicle.¹¹ Without knowing the reasons for nominated drivers living outside a five mile radius, this risks being an overly blunt tool that may in fact restrict the mobility of disabled people.

The affordability of Motability

The Review was worried to learn that in some instances individuals were choosing not to use the Motability scheme as it was too expensive. Additionally, there were problems due to Motability using all an individual’s mobility component, leaving no money available for other mobility needs.

“Didn’t use mobility component to purchase through Motability as type of vehicle needed...meant that on top of losing mobility component private funds had to be supplied to sum of approx £8000 and this would need to be repeated every three years when lease on vehicle ended and new contract with new vehicle had to be supplied. Cheaper to privately fund initial vehicle which has only had to be replaced once. Current vehicle is eight years old and not in need of replacement.”

There was a similar issue for families, where sometimes the extra payments required in purchasing the Motability vehicle meant there were no resources left to purchase an additional, non-adapted family car.

Motability does offer a grant scheme and some, but not all, adaptations are free, but based on some of the evidence received, the Review would be keen to find out more about how Motability ensures everyone gets the best possible value out of the scheme.

Based on the evidence received by the Review over the cost of Motability cars, it would be keen to see further work undertaken to evaluate how to ensure that the current Motability scheme offers the best value for money to disabled customers.

**Recommendation 3:
Motability should initiate a review into how the role it plays in supporting disabled people’s independence could be further improved. In particular it should have reference to the value for money of Motability, especially in context of wider mobility needs not met by an adapted vehicle, and should**

¹¹ See: www.motability.co.uk/main.cfm?type=NI&ObjectId=2779

seek to identify any barriers to individuals maintaining direct control of their Motability vehicle.

8.8 Key findings

- DLA mobility provides personalised support built around the individual.
- The removal of DLA mobility or its successor PIP, would lead to a loss of independence, choice and control for disabled people.
- Proposals to remove DLA mobility appear to be based on an outdated view of residential care.
- Removing DLA mobility could have a negative impact on the mental health of people living in residential care.
- Removing DLA or PIP mobility from people living in residential care would create a two tier system where self-funders or people receiving care in their own home retained the mobility component and the personal support that comes with this, whereas those living in residential care did not.
- Many people have someone else managing their DLA. The long-term goal should be for more people to have direct control over their benefit.
- Any removal of DLA mobility would prove a set-back for disability rights and would run counter to the progress made on personalisation and choice.

9. The responsibilities of local authorities in meeting mobility needs

“When assessing the community care needs for adults of working age in residential care homes, we assume that all their needs are met within the contract price which is to purchase 24 hour care. The only assessed mobility need we accept is to attend day opportunities.” Local authority

Overview

Mobility needs do not tend to form a major part of an individual’s community care assessment, and in particular local authority interpretations of ‘assessed need’ are unlikely to include ‘personal’ mobility needs, such as visiting friends and family. Where mobility is factored into care packages at all it is generally to meet mobility needs that are related to *specific care* needs identified by the local authority as eligible for services.

Eligibility for social care, including any mobility needs that may be met, is determined through the community care assessment.¹² This assessment is a legal requirement for anyone who ‘may be in need of any such services and identifies an individual’s needs in relation to social care. These needs are then matched against the four different eligibility bands in line with Fair Access to Care Services criteria.¹³ It is for each local authority to decide which bands (critical, substantial, moderate and low) are eligible for services. Currently 74% of local authorities meet only ‘substantial’ or ‘critical’ needs.¹⁴

Previous evidence collected on this issue¹⁵ suggested three things. Firstly, that mobility needs tend *not* to form part of an individual’s community care assessment, and, related to this, that local authority interpretations of ‘assessed need’ are unlikely to include ‘personal’ mobility needs. Secondly, that even where an individual does have identified mobility needs, these may not be eligible for support according to local authority criteria. Thirdly, that where mobility needs are factored into care packages this is to meet specific mobility needs related to specific care needs – for example, to support attendance at a day centre.

9.1 Legal obligations and guidance

The call for evidence asked local authorities to provide details of any legal obligations in relation to the mobility needs of disabled people living in residential care. Local authorities referred to a wide range of different pieces of legislation

¹² NHS and Community Care Act (NHSCCA) 1990 S47(1)

¹³ ‘Fair access to care services - guidance on eligibility criteria for adult social care’: this is the eligibility framework set out by the Department of Health which is adopted by local authorities. This guidance has recently been superseded by ‘Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care’, although the eligibility banding remains the same with four bands of need: low, moderate, substantial and critical. Each local authority has its own policy around which bands are regarded as eligible for services, and therefore which needs will be met by the local authority. The term ‘FACs criteria’ remains commonly used.

¹⁴ *Cutting the Cake Fairly: CSCI review of eligibility criteria for social care* October 2008

¹⁵ See: *Don’t Limit Mobility*, January 2011, and *DLA Mobility: Sorting the facts from the fiction*, March 2011: www.disabilityalliance.org/dbc3.htm

and guidance, but there was little consistency in local authorities' interpretation of their responsibilities with regard to personal mobility.

9.2 Individuals' views of their community care assessment

The call for evidence asked individuals to provide details of what their community care assessment or care plan stated with reference to their mobility needs. Where people knew the contents of their assessment or plan, most references to mobility were unspecific and rather generalised. Further, where needs were described, there was no real reference to how or by whom they should be met.

"It says that I need to be supported to go out."

"It states it is important that I access the community for my wellbeing."

9.3 Local authorities' approach to mobility in community care assessments

Responses from local authorities suggested that whilst wider mobility needs, for example, going to a leisure centre or meeting friends and family, might be identified in a community care assessment, in most cases the only needs that are eligible for funding are those relating to an assessed care need according to local authority eligibility criteria.

"Where a person is assessed as having an eligible need for a service, consideration of their transport to access the service is considered part of the 'eligible need' which [local authorities have] a duty to meet." Local authority

"We assess where people need support to manage or improve their mobility but do not fund support to access transport unless it relates to accessing a social care service." Local authority

"We meet all critical and substantial needs defined by FACS, and if these include mobility needs, we endeavour to meet them." Local authority

The call for evidence asked local authorities what they considered as assessed needs. Whilst again there were a variety of views, more considered attendance at a day service to be an assessed need (62%) than activities such as going shopping (37.5%), meeting with friends (30%), and volunteering (25.6%).

In general, the Review found that mobility was considered only when meeting a specific care need, rather than as an outcome in itself.

"Mobility is often a crucial issue for meeting needs, but is not in itself an outcome which we guarantee to achieve." Local authority

Peter Hay, president of the Association of Directors of Adult Social Services (ADASS), reinforced this view. He stated that, as a generality, mobility sits

outside the remit of local authority funding responsibilities and if mobility were to be covered at all, this would be in relation to meeting specific care needs.

It was noted that disabled people will have mobility needs unrelated to their assessed care needs. As a consequence, personal mobility needs remain outside local authorities' remit, and a number of witnesses felt that other entitlements, including DLA as an 'extra costs' benefit, reflected this.

Local authorities were concerned that should the proposed removal of the mobility component go ahead, they would lack the resources to meet any shortfall. Respondents and witnesses stated the inability of local authorities to pick up any additional personal mobility related costs, particularly within the context of the wider crisis in social care funding.

“[The] Council is concerned that the removal of DLA mobility...will inevitably lead to a shortfall in income for residential providers, and that providers will seek to remedy the position through increased fees.” Local authority

“Councils would have a policy decision to make about whether they put their hand up to take on additional responsibility in the light of this. Councils are free to make their own decisions but bearing in mind the general weight of pressure going onto Councils, and remember we’ve got two more years of reduction in Council expenditure already programmed into the calendar...” Peter Hay, ADASS

9.4 Contractual arrangements with providers

Local authorities were asked what they specifically paid providers to deliver in terms of mobility. Whilst most referred to meeting assessed social care needs, in many cases there was a much broader assumption that local authorities were purchasing an all-inclusive package of support from providers and that mobility should therefore be covered.

“Local authorities’ contracts with care homes will cover services to meet a resident’s assessed need.” Local authority

“If a service user lives in a residential home, the home will make all the transport arrangements – the cost is included in the cost of the placement.” Local authority

However, it was still acknowledged that there were personal needs above and beyond those within the contract price that should be met via the home and/or through the individual's DLA mobility.

9.5 How local authority support interacts with DLA

Local authorities are prohibited from taking into account an individual's DLA mobility when determining how much they should contribute towards their residential care.¹⁶ Of those local authorities who responded to the call for evidence, 14 (37%) specifically stated that DLA mobility was ignored or disregarded completely in line with the Charging for Residential Accommodation Guide (CRAG).

“The benefits we take into account for people in residential care are covered by CRAG which is laid down nationally and which we are obliged to follow. Mobility allowance is excluded from the financial assessment under CRAG.” Local authority

However, it was clear that a small number of local authorities,¹⁷ while excluding DLA for the purposes of means testing, allowed it to be used to meet an assessed need. In these cases, DLA mobility was seen by the local authority as providing a 'base line' level of support with local authority funding (in relation to mobility) being regarded as a 'top-up' to this.

“We assume that people will use mobility benefits to meet mobility needs, and would usually only provide additional support if that was necessary in order to meet the person's wider critical needs.” Local authority

“Our obligation is to arrange care and attention for people...Where people are eligible for DLA mobility, we would assume that this is available as the first source of funding to enable them to get out and about, though we would consider additional funding if someone's needs could not be fully met using DLA mobility funding.” Local authority

DLA mobility is for personal use and should not be designated to meet assessed needs.

Recommendation 4:

The Department of Health should revise the Charging for Residential Accommodation Guide to make clear that the mobility component is to be completely disregarded by local authorities, both in means testing and in establishing how to meet assessed needs. Equivalent action should be taken in Scotland and Wales.

Recommendation 5:

The Department of Health should write to all local authorities drawing their attention to the revised Charging for Residential Accommodation Guide and emphasising the requirement for local authorities to meet all assessed mobility needs. Equivalent action should be taken in Scotland and Wales.

¹⁶ Section 8: *Charging for Residential Accommodation Guide (CRAG)*, Department of Health, 2011

¹⁷ This was implied in seven individual comments by local authority respondents.

9.6 Personalisation in residential care

Social care is becoming more personalised, with provision increasingly built around the individual. Many people receiving care in their own home can now receive a personal budget and in some cases direct payments, which are aimed at placing much greater control in the hands of the individual.

Currently residential care is exempt from personal budgets but the long-term intention is to introduce the same approach in residential care, reflecting the recent proposals from the Law Commission for updating social care legislation in England and Wales.¹⁸

DLA mobility ensures that people living in residential care have some direct control over the support they require. It has been suggested that with increased personalisation, social care support and benefits could be merged.¹⁹ However, witnesses at oral evidence sessions felt the social care system was not developed enough for this to be possible.

“What we’re talking about here is disabled people having confidence and...without that confidence in the social care system, I think it’s better to have confidence in a flat rate even if it’s a bit non personalised.” Liz Sayce, Radar

Witnesses were particularly keen to stress that it is DLA mobility that offers a level of personalisation currently missing in other aspects of residential care and it would be a counterintuitive step to remove the benefit.

9.7 Key findings

- There is inconsistency among local authorities in how they meet mobility needs.
- Local authorities generally meet only those mobility needs relating to eligible social care needs; mobility is not seen as an outcome in its own right.
- Contracts with providers rarely make specific reference to mobility needs, with the assumption that these are included within the overall contract price.
- There is no overlap between local authority funding and the support offered by the mobility component. DLA mobility is responsible for personal mobility needs, whilst local authorities seek to meet those mobility needs relating to eligible social care needs.
- In some cases DLA mobility is seen as a base line for mobility support, that local authorities supplement if necessary.

¹⁸ It is a recommendation by the Law Commission that the reform of social care allow for direct payments to be extended to residential care. See recommendation 35: www.justice.gov.uk/lawcommission/publications/1460.htm

¹⁹ *Shaping the future of care together*, Department of Health, July 2009: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102732.pdf

- Social care is becoming increasingly personalised. Whilst residential care has yet to see the introduction of direct payments, DLA mobility provides a vital area of support over which individuals already have complete control.

10. The role of residential services in meeting mobility needs

“We are registered care homes, so providing transport is part of the contract with the local authority. However, some costs, such as visits to family and friends are not covered by the local authority.” Provider

Overview

In many cases mobility needs are not specified in contractual arrangements between local authorities and care homes. Any reference to mobility tends to be in relation to mobility support associated with an assessed care need, rather than ‘personal’ mobility. In some cases residential services had policies on the collective use of the mobility component.

10.1 Contractual arrangements with local authorities

The Review found that there was little consistency among providers about what they were being paid to provide in relation to a number of different forms of mobility support. However, there were significantly higher numbers stating that they received no funding at all in relation to certain activities. For example:

- 85% stated that they were not funded to provide for the cost of taxis or petrol money to visit family and friends;
- 78% stated that they were not funded to provide for the cost of taxis or petrol money to attend leisure activities, such as a theatre or music group.

Reinforcing the findings from local authority responses, care home providers said that mobility needs are specified in contractual arrangements only in some cases, and in many cases not at all.

Witnesses providing oral evidence on behalf of providers of residential care suggested that in the majority of cases where any reference to mobility was made or implied, this was more likely to be in relation to the day-to-day aspects of mobility support (for example, getting to a day service) associated with their care package. More individualised needs above and beyond this were not specified and could not be met by the provider. A number of providers were aware of more general references to the provision of ‘24 hour support’ but stated there was no specific instruction in relation to transportation or mobility costs.

“It is an essential assessed requirement, but we receive no dedicated or specified funds to provide them.” Provider

Many providers also said that contractual arrangements that were agreed at the time an individual entered residential care (in some cases ten or twenty years ago) were no longer adequate. Attitudes to residential care have changed from the historical approach with less focus on the individual and an assumption that people would share services and support, to today’s emphasis on choice and control. The mobility component itself has played a part in this change, providing

at least one area of an individual's support package where they have complete control.

“We perhaps are being paid to support people who five years ago...were accessing day centres through the use of community transport and when we first started supporting them that was the agreement and that was the contract... Obviously in a lot of areas community transport has now stopped and people are expected to make their own way to the day centres...Now they're not receiving more money for that and we're certainly not receiving any more money for that.” Marianne Selby-Boothroyd, Certitude

“One of the...things in particular they point out...is around independence and the ability to use their DLA mobility away from staff. Not having to ask staff, not having to rely on staff and not having to explain and to be able to book themselves a cab to be able to go off and do whatever it is they want to do.” Marianne Selby-Boothroyd, Certitude

However, in a number of cases, providers noted that there was an expectation by local authorities that individuals contribute their mobility component towards their mobility needs. One provider explicitly described the local authority changing their funding allocation as a direct consequence of the introduction of DLA mobility; DLA mobility was expected to supplement the support individuals received from the local authority to meet those mobility needs associated with care provision. The benefit should not be seen as a substitute for local authority funding.

Recommendation 6:

Contracts between local authorities and care home providers should clearly specify any funding arrangements in relation to the provision of mobility support required in meeting assessed needs. Care Quality Commission inspections should review provider contracts with local authorities and report on whether these clearly specify all assessed mobility needs and the providers' responsibility in meeting these. Equivalent action should be taken in Scotland and Wales.

10.2 Funding pressures

The Review found a recurring theme expressed by providers in relation to increasing funding pressures. Where providers specified the provision of some mobility support as part of their core costs, this tended to be in relation to shared vehicles attached to the home or staff time, with DLA mobility being used to enable more individualised trips by residents. A number of providers felt under pressure from their local authority to reduce their core costs, in relation to both care and mobility. Additional pressures were seen in relation to other mobility-

related schemes in some local areas, including Dial a ride²⁰ and taxicard entitlements.

Many providers were already subsidising transport costs and, as local authorities seek further savings on the price they pay for social care, were uncertain about what they would do if support was cut further.

“We strive to be excellent in all that we do and we support the involvement, independence and development of all of our service users, in every possible way that we can. The reality is that we very often...do this at our own financial cost.” Provider

“We already subsidise their transport costs and cannot see how we would be able to maintain the busy lifestyles our residents enjoy if their mobility money was to stop.” Provider

Providers felt that policy and practice developments around supporting choice and independence for disabled people, alongside increasing financial demands on both local authorities and providers – therefore leaving them unable to meet more than those core needs established in the community care assessment – were only increasing the importance of the role of DLA mobility.

10.3 Policies on usage of DLA mobility

The Review was aware of some instances of disabled people handing over or ‘pooling’ some or all of their DLA mobility money to their service. It therefore sought to establish (i) how widespread this practice was, (ii) whether or not it was voluntary and (iii) how much of their DLA mobility people were pooling.

Individuals providing written evidence were asked whether or not their residential service had a policy around the use of DLA mobility. In many of the responses, it was unclear whether the policy was with regards to what individuals were expected to use their DLA to cover, handing over a proportion of their DLA to pay for shared mobility provision, or in relation to how DLA was used to meet transport costs (for example, a contribution towards petrol costs).

“DLA used for everything other than going to the day centre.”

“70% of DLA is used by the home to fund mobility needs. The other 30% is paid into personal account for personal use i.e. paying towards (not fully) costs of visiting family regularly.”

“I contribute towards fuel for the journeys that I make in the home’s vehicle.”

²⁰ Dial a ride is a transport scheme for people with disabilities. It is run on a local basis and varies from area to area. Respondents described the scheme as impersonal and inflexible. People described having no control over the time of their journey and the journey taking much longer due to pick ups and drop offs. In many cases, DLA mobility is used to pay for or contribute to the cost of a Dial a ride journey.

“...if I use the home’s vehicles I have to pay towards petrol...”

10.4 Collective use of mobility component

In some cases, it was clear that there was an expectation on service users to contribute a percentage of their DLA mobility to provide for collective usage. In other cases, this was a voluntary option.

“There are a number of people that do pool their mobility to contribute to a shared vehicle but again that is their choice to do so. And if that leaves them some money to use towards that vehicle to get around and some additional money to keep for themselves to use in other ways then again that’s an aspect of personal choice.” Hayley Jordan, DBC

It is important to recognise that in some instances, collective usage of DLA mobility can offer better value for money, enabling recipients to purchase a wider package of support. The Government’s recently published vision for social care actually acknowledges the value of pooling personal budgets.²¹

“Pooling budgets is one way of maximising outcomes, using direct payments to employ an organiser to help a group of people to arrange leisure activities together.” A Vision for Adult Social Care

What is important is that individuals are able to choose whether or not to pool their resources, rather than have this imposed on them. Disabled people living in residential care should have the same choice and control in relation to how their DLA mobility is spent as people receiving care in their own home. Collective usage of money should be an option for residents, not a requirement. There are clearly challenges in this approach. For example, if six residents choose to combine a percentage of their DLA mobility to lease a shared car and one resident leaves and a new resident does not want to join the arrangement. However, managing the process should be no different to any collective funding agreement among people living outside of residential care, it needs to be a fully informed, voluntary decision and if there is a change, such as one member of the group leaving, it is for the remaining members to discuss possible options and decide what action to take.

The Review believes that the collective usage of DLA mobility as an option should not automatically be dismissed as bad practice, as long as the arrangement is service-user led as opposed to service led.

“If they live together and they’re going to the same place together they may well pool [money] like anyone else would to pay for the cost of a cab or petrol but there’s no [set] contribution.” Marianne Selby-Boothroyd, Certitude

²¹ A vision for adult social care: capable communities and active citizens, Department of Health, November 2010: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508

“They’ll [the service] hold...a review for that person or a best interests meeting if we require that it needs a substantial contribution...” Natasha Kolicic, NAS

If there is an agreement by residents to contribute some of their DLA mobility to the care home up front, for example, for the collective use of a shared vehicle, it must be clear that this contribution is towards supporting personal mobility costs (as is the intention of DLA mobility) and not as a prop by care homes or local authorities to cover the mobility costs associated with assessed care needs. Although this did not appear to be widespread, the Review believes it is nevertheless an issue that needs to be addressed to ensure that the individual has full use of their DLA mobility for their personal mobility needs.

Recommendation 7:

The Care Quality Commission²² should revise their “Guidance about compliance: Essential standards of quality and safety” in relation to Regulation 19 of the Care Quality Commission (Registration) Regulations 2009, outcome 3 in order to make clear that any policies on charging for service transport or pooling the mobility component must be transparent and must provide choice and control to the individual. Equivalent action should be taken in Scotland and Wales.

10.5 Transport costs

Individuals did regularly cite charges from providers for using service transport. It was often unclear from responses whether people were being charged for those journeys relating to assessed needs, or for personal journeys. The Review would be concerned if individuals were being charged to use service transport when this formed part of meeting their assessed care needs. However, if the service transport is being offered as an alternative to taxis or local public transport then, provided any charging policy is fair and transparent, this can provide a positive addition to existing options.

10.6 Specific guidance and legislation

The report *DLA mobility: sorting the facts from the fiction*²³ unpicks some of the requirements on care homes in relation to Regulation 17 of the Health and Social Care Act 2008 and the Care Quality Commission (CQC) guidance in relation to Regulation 17. In both cases, there are no specific references to mobility provision, but rather more generally in relation to ensuring the wellbeing of residents through the promotion of independence and community involvement. There are no specific references to how this might be met in terms of funding.

In addressing the specific requirements of the CQC guidance, in relation to enabling service users to be an active part of their community and providing

²² The Care Quality Commission (CQC) is the independent regulator for all health and social care services in England.

²³ *DLA Mobility: Sorting the facts from the fiction*, March 2011:
www.disabilityalliance.org/dbc3.htm

opportunities and support to promote their autonomy, providers tended to respond more generally in relation to the promotion of independence and less specifically with reference to the mobility needs of individuals. Peter Hay, President of ADASS, supported the view that there was no specific reference to mobility, but noted that the vast majority of care providers want to do the best they can for the people they support and that part of the approach to provision is about identifying and supporting good practice in relation to all aspects of an individual's wellbeing.

“So if CQC were to meet a resident at a home who said, “look, what I’ve been doing is banging at the doors wanting to go out”, then I think CQC would regard that as an issue of dignity as I would hope the social worker reviewing the needs of that person would also be picking up. So I think if it had become an issue you would have had both the general motivation of the provider and the kind of orientation of the system towards a dignified response to meeting people’s needs.” Peter Hay, ADASS

10.7 Key findings

- Mobility needs are specified in contractual arrangements only in some cases. Where reference is made this is often in relation to the day-to-day aspects of mobility support associated with the assessed care needs of individuals; needs above and beyond this in terms of more individualised requirements are not specified.
- Where mobility support is provided by providers, this is often through the use of shared service vehicles with DLA mobility being used to support more individualised trips.
- The changing (often increasing) mobility needs of individuals are often not acknowledged through community care assessments or through additional funding.
- Many providers feel under pressure to reduce their core costs, both in relation to care and mobility.
- Many providers are already subsidising travel costs and would be unable to meet any further shortfall in funding.
- Some providers require residents to ‘pool’ some or all of their mobility component for collective use.
- Some providers charged people to use service transport although it was often unclear whether this was for assessed needs or personal use.
- Legislation and guidance in relation to the responsibilities of care homes make no specific reference to mobility needs, focusing more generally on promoting independence.

11. Residential schools and colleges

“DLA mobility means I can return home to my family at weekends. Surely, it would cost much more if I need to go into full time residential care just because my family cannot afford a WAV [Wheelchair Accessible Vehicle]”

Overview

There is a distinction between funding for mobility provided by the school or college, which is generally used to fund mobility costs relating to curriculum activities, and funding from DLA mobility or private income, which is used to fund non-curriculum activities. Mobility tends not to be specifically referenced in contractual arrangements with colleges, but there is an assumption that colleges will provide some level of mobility support because mobility forms part of the curriculum.

Although the Low Review has concentrated on the personal mobility needs of disabled adults living in state-funded residential care homes, the call for evidence was extended in order to consider young disabled people aged 16 or over who were attending a residential school or college who would also be affected were the mobility component of DLA or PIP to be removed.

11.1 Mobility needs and support

The call for evidence asked young people attending a residential school or college to provide details of the mobility support they required for a range of activities including getting to and from college at weekends and at the beginning and end of term, taking part in leisure activities, visiting friends and family, going on school outings and going shopping as part of curriculum learning.

Respondents indicated they required a wide range of mobility support for all activities, including:

- Support from an individual
- Use of a powered wheelchair
- Use of an adapted or Motability car
- Transport provided by their school or college
- Use of a family car

In many cases more than one method of support was needed. Notably, no respondents indicated they did not need any support or used public transport to undertake these activities.

Witnesses and respondents noted the relationship between mobility and the independence of young people as they prepare for adulthood.

“[It is crucial that young people are]...able to manage their own money rather than have it be in the hands of an institution or a school. How vital

that is in terms of citizenship, and in terms of family life and the ability for them to maintain contact at the weekends and after school with their families.” Laura Courtney, EDCM

11.2 How mobility needs are met

Views of individuals

A distinction was made between which funding streams were used to support certain activities, depending on whether or not the activity was part of the school curriculum. For example, eight of ten respondents stated that the school/college funded the mobility or transport needs of ‘going shopping as part of the learning curriculum’, with no respondents stating that DLA mobility funds were used for this. In contrast ‘going shopping for personal needs’ was overwhelmingly reported to be funded by DLA mobility or through private income.

Similarly, respondents reported that getting to and from college or school at the weekends (for week day only residents) or at the beginning or end of term, was funded by DLA mobility or the family, and not by the school or college.

“In coming here I sought some views from the National Association of Independent Non-Maintained Special Schools (NASS)...but they said specifically that the families would go with their young people, would collect them [from school] and take them to hospital appointments and that the mobility component would be used to support that.” Laura Courtney, EDCM

When asked about mobility funding during holidays and weekends respondents indicated that all mobility needs were funded by DLA mobility, the individual, or their family, with the exception of school outings.

Views of organisations and providers

Responses showed that schools would meet curriculum based mobility needs and some leisure needs, but that DLA mobility allows young people to spend time with their families, go out independently, have flexible mobility support (not having to pre-plan every activity) and attend hospital appointments.

“Transport provided by an education or care provider is often limited, with no extra provision for meeting with friends and family, weekend visits, day trips, going shopping for personal items or extra curricular activities including accessing leisure activities.” Laura Rodrigues, The Children’s Society

It was also noted that it would be a hugely detrimental step if schools were to take control of personal mobility needs as this was one aspect of students’ lives that is ‘non-service’ based. The view was that young people’s lives are service based enough and filled with constraints because of the residential setting, so

that anything that puts more control into the hands of the school rather than the young person would be regrettable.

“As you prepare for adulthood you have to be able to begin to be financially independent, to take your own risks, within reason, but as any teenager would. To suddenly take any of that ability away from children who are already significantly facing barriers and exclusion would be detrimental to their personal development.” Laura Courtney, EDCM

11.3 Contractual arrangements

Young People’s Learning Agency (YPLA)

The Young People’s Learning Agency (YPLA) is sponsored by the Department for Education and exists to support the provision of further education and training for young people aged 16-19 in England, including those young people who are under the age of 25 and subject to a learning difficulty assessment.

From the college perspective, Anne Price, Director of Education at specialist college David Lewis, and Vice Chair of the National Association of Specialist Colleges, stated that whilst mobility is not specifically referenced in the contractual arrangements between Colleges and the Young People’s Learning Agency, there is an assumption that colleges will provide some levels of mobility support given the inclusion of mobility in elements of the curriculum, for example, travel training. She noted that there is an expectation by Ofsted²⁴ inspectors that young people are out learning the full range of skills they need, including those relating to mobility.

However, in terms of how this mobility support was funded, there was an expectation by some colleges that students would contribute part of their DLA mobility to allow for the more personalised elements of mobility support. This reflects the Review findings in relation to residential care provision, with mobility support attached to an assessed care need being funded by the local authority and provided by the care home provider, and more personalised mobility support being funded through individual’s DLA mobility. It was unclear from the evidence gathered whether this more ‘personalised’ mobility support was in relation to non-curriculum based activities only (see section 11.6). Additionally, there was the added complication of the care aspect of residential educational provision being provided for by the local authority, but the view was expressed that:

“Assumptions are made at care assessment time that an individual will be using their benefits...for whatever means, whether it’s contributing towards the care package or in the case of travel and getting out and about they’ll use their DLA mobility for that and that’s assumed and accounted for.”
Anne Price, NATSPEC

²⁴ Ofsted is the Office for Standards in Education, Children’s Services and Skills responsible for inspecting and regulating services which care for children and young people, and those providing education and skills for learners of all ages.

The impact removing DLA mobility would have on students

When asked about the impact the proposed removal of DLA mobility would have on young people in residential school/college, witnesses and respondents were clear that it would result in a loss of independence for young disabled people. In particular, there was great apprehension in relation to the potential loss of contact with family. These views echo those the Review heard in relation to residential care.

Limited local learning opportunities can often mean that, for many disabled young people, residential educational settings are the only option if they want to pursue post-16 education. Young people would therefore be faced with the choice of pursuing their studies and losing their independence with the loss of the mobility component, or staying at home and keeping it.

“Jane is in her final year of school... This facility has no transport of its own so the only time Jane goes out is when her family take her in her vehicle.... Therefore, without her vehicle she be unable to go out with myself or her Dad, she will be unable to visit home therefore missing out on family occasions, birthdays, Christmas etc. She won't be able to visit her grandparents or go on shopping trips, which she loves. She won't be able to attend any college courses or visit her friends who may well be in other care homes...I could go on and on about how unfair this proposal is but suffice to say my daughter's life will be radically changed for the worse should this go ahead.”

11.4 Young people's rights

Witnesses pointed out that the UN Convention on the Rights of the Child applies to those young people up to the age of 18, and includes rights to access community and leisure. There was concern that the removal of DLA mobility and the corresponding removal of choice and control from the recipient might be in contravention of this right.

UN Convention on the Rights of the Child

Article 31

- 1) States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
- 2) States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.”

11.5 School or College policies in relation to usage of DLA mobility

Only four individuals who responded to the call for evidence answered the question about whether their school/college had specific policies regarding usage of their DLA mobility. All of them stated that this was not the case at their particular school or college. However, it was noted during the oral evidence

sessions that some colleges do ask students to contribute a flat rate per week from their DLA mobility towards their mobility support. There was an emphasis on the students then planning their week by week (non-curriculum based) activities based on this financial contribution.

“They plan what they want to do week by week...Hopefully most of them want to go and live in supported living when they leave so it’s trying to get into that way of working with each other, managing your money, planning what you can do with a certain amount of money...” Anne Price, NATSPEC

The Review appreciates that there is a distinction between the circumstances of 16-year-olds at a residential school or college, where parents and the school might be expected to play a role in managing budgets, and adults living in a residential care home. However, concerns remain that mandatory policies around how DLA mobility is used could well work against the intention to support the transition of young disabled learners into adulthood and the element of financial independence that brings with it. The Review was unable to explore this in any greater detail and was limited by the low response rate to the schools/colleges call for evidence, but would welcome further work by the relevant regulatory bodies to consider this issue in more detail.

11.6 Motability

The Review was aware of some claims of ‘bad practice’ whereby a young person’s DLA mobility was being used to fund a vehicle that was then used by family members for the majority of time. Eight out of ten respondents answered the question in the call for evidence about whether or not they used their DLA mobility towards the cost of a Motability vehicle. Five of them stated that they did and that the vehicle was kept at the family home, with one respondent stating that the vehicle was kept with them at school/college.

As with Motability for over 16s, it is important that work is done to establish the role Motability vehicles play in supporting individuals to maintain an independent life, and any barriers that individuals or families may face in making the best use of their Motability vehicle. This should happen before any decisions are taken on reforming the scheme.

“The ‘mobility allowance’ even at its current level, is not sufficient to pay for buying, adapting and running his disabled vehicle. His insurance alone (because he has to insure other people to drive) is massively expensive and has risen 30% this year. The cost of adapting his vehicle (lowered floor etc) was almost as much as the cost of the base vehicle itself. We ran his previous vehicle for 13 years to keep the total cost down, his current vehicle is 6 years old and we hope to run it as long as we can. We did not use Motability as the cost of adapting a vehicle through them was prohibitive.”

11.7 Key findings

- While curriculum based activities relating to mobility are paid for by the college and/or via the YPLA, those activities associated with personal needs are expected to be met by a young person's DLA mobility.
- It is extremely important that young people attending a residential school or college are able to maintain relationships, particularly with family members.
- Young people attending a residential school or college should be fully supported to prepare for adulthood, including in relation to having some element of financial independence and the aspects of choice and control that come with that.

12. Mobility as a right

“We all have the right to participate in society...rights are about participation in a whole range of activities. And if you can’t do that because you simply are not able to be mobile then...that is a real constraint on you being able to exercise that right.” Liz Sayce, Radar

Overview

The ability to exercise choice and control over mobility is fundamental to the exercise of rights defined by the UN Convention on the Rights of Persons with Disabilities, including the right to education, the right to employment and the right to be included in your community. Witnesses and respondents commonly described the negative impact and wide ranging implications that a lack of mobility support would have on people living in residential care

The Review considered how important mobility is to disabled people’s independence, and looked in particular at whether there is such a thing as a right to mobility. Previous work on this issue highlights the UN Convention on the Rights of Persons with Disabilities, which includes the right to personal mobility²⁵.

UN Convention on the Rights of Persons with Disabilities

Article 20 – Personal mobility

...take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- a) facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost
- b) facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost.

However, the Review found that witnesses presenting oral evidence focused more on the importance of mobility to securing other rights, rather than mobility as an intrinsic right in itself.

“If you think about all the different aspects of the UN Convention on the Rights of Persons with Disabilities you’re covering areas like education and employment and the whole range of areas. And actually, they depend on mobility.” Liz Sayce, Radar

As well as including the express right to personal mobility, the UN Convention on the Rights of Persons with Disabilities includes the right to education, the right to employment, the right to be included in your community and many other rights. These all rely on the ability to exercise choice and control over your mobility.

²⁵ See: *Don’t Limit Mobility*, January 2011 and *DLA Mobility: Sorting the facts from the fiction*, March 2011: www.disabilityalliance.org/dbc3.htm

12.1 The right to family life

Whilst the Review did not specifically ask individuals to provide written evidence for their views on the right to mobility, many talked about what support with personal mobility enabled them to do and many focused on family life. Submissions made clear that any removal of DLA mobility would have a negative impact on family life.

“My family are very, very important to me and I love to go out and home to visit them, this would not happen if I lose my mobility money.”

“The car is the only way of escaping for some private time with my family...hearing my children play in concerts. If the car is taken away, I will only be able to go on outings with all the others. My private life at home with my family will be taken away. It is the only good thing I have left.”

It could therefore be argued that the removal of the mobility component would seriously impact on the Human Rights Act, Article 8: right to respect for private and family life.

12.2 Mobility and safeguarding

Witnesses described the negative impact and wide-ranging implications that the potential removal of mobility support could have on people living in residential care. This was often linked to wider concerns about participation, but in some cases it was noted that the inability to participate in society brought about by inadequate mobility support could leave disabled people more isolated and therefore less able to report any instances of institutional abuse should they be exposed to it.

“...the removal of the ability to participate with friends, with family, with any basic engagement in society does pose a potential risk that some disabled people may become incredibly isolated and at higher risk of institutional abuse....The risk here is that if disabled people don't have the choice and control over the resources, care homes... may have a greater ability to hide instances of abuse, be it physical, sexual or whatever it might be. And that prevents the disabled person having that crime, whatever it is, stopped.”
Neil Coyle, Disability Alliance

“Removing the mobility component could also make care homes themselves more isolated. Regular visits to and from family and friends is one of the things that helps prevent the sort of abuse we saw at Winterbourne View.”

12.3 Key findings

- The UN Convention on the Rights of Persons with Disabilities provides disabled people with the right to mobility.
- The ability to exercise choice and control over mobility is fundamental to the exercise of other rights, including the right to education, employment and family life.
- Removal of the right to enjoy personal mobility risks isolating people, leaving them with less opportunity to report any instances of abuse.

13. Conclusions

“You should have the ability to be able to fulfil your aspirations, whether your home is...your parents’ home or a home that you have in the community, or just happens to be a residential home...”

And as part of choice and control people should be able to choose where they live and what they want to do in their daily life...It is essential...that people in residential care can control that mobility component in exactly the same way as other people who will be receiving the Personal Independence Payment.” Sue Bott, NCIL

Everyone has mobility needs, but for disabled people additional support is often needed in order for these needs to be met.

This support can take many forms, from specialist wheelchairs to support workers, but the common theme is the need for appropriate funding.

Disabled people’s mobility needs can broadly be split into two - those that relate to assessed social care needs and those that relate to more individualised or personal needs. For example, many people will have mobility needs related to the requirement to attend a day service or other provision related to their care needs. In contrast, personal mobility relates to things like visiting family and friends, maintaining a social life and staying active in the community. Similarly, in residential school or college, young disabled people have personal needs distinct from the care or curriculum elements of their educational package. At times these needs can overlap but the majority of the time they are distinct.

DLA mobility plays a vital part in meeting personal mobility needs. It provides people with choice and control over how their needs are met and allows for a personalised solution. If this benefit were to be removed from disabled people living in residential care or attending a residential school or college, there is no alternative provision to take its place. Its removal would lead to disabled people becoming increasingly isolated from their communities and family and being denied basic human rights.

Local authorities have a responsibility to meet those mobility needs related to an individual’s social care needs, but those social care needs which are not deemed to be ‘critical’ or ‘substantial’ are unlikely to be eligible for services, and therefore any related mobility needs will remain unmet. In a small number of cases there is an assumption by local authorities that DLA mobility will meet or contribute towards even those ‘assessed’ needs – therefore impacting on disabled people’s ability to meet their personal mobility needs.

Providers of residential care try to ensure mobility needs are met, but are not funded to provide for 'personal' mobility needs. If there is a lack of clarity or no specific funding from local authorities for assessed mobility needs, this is, alongside additional pressures to cut costs as local authorities tighten funding, making it increasingly difficult for services to provide mobility support. However, the solution is not for providers to require people to hand over a share of their DLA mobility as happens in some instances. Rather it is for local authorities to fully assess and fund those mobility needs related to social care provision, ensuring providers are fully funded to meet their responsibilities as regards mobility.

DLA mobility provides individuals living in residential care with independence. It is one area of their lives over which they have complete control and its removal would be a significant step backwards for disability rights. Whilst action needs to be taken to ensure that local authorities fulfil their responsibilities for funding those mobility needs relating to social care provision and that providers are allowing individuals complete control over how their DLA mobility is used, the overarching priority is the retention of DLA mobility and the independence it brings to disabled people living in residential care.

14. Recommendations

Recommendation 1:

As Personal Independence Payment is introduced, disabled people living in state-funded residential care should be eligible to receive the mobility component on the same basis as disabled people receiving care in their own home.

Recommendation 2:

The Department of Health should develop a peer led initiative encouraging and supporting people living in residential care to directly manage their Personal Independence Payment mobility component. Equivalent action should be taken in Scotland and Wales.

Recommendation 3:

Motability should initiate a review into how the role it plays in supporting disabled people's independence could be further improved. In particular it should have reference to the value for money of Motability, especially in context of wider mobility needs not met by an adapted vehicle, and should seek to identify any barriers to individuals maintaining direct control of their Motability vehicle.

Recommendation 4:

The Department of Health should revise the Charging for Residential Accommodation Guide to make clear that the mobility component is to be completely disregarded by local authorities, both in means testing and in establishing how to meet assessed needs. Equivalent action should be taken in Scotland and Wales.

Recommendation 5:

The Department of Health should write to all local authorities drawing their attention to the revised Charging for Residential Accommodation Guide and emphasising the requirement for local authorities to meet all assessed mobility needs. Equivalent action should be taken in Scotland and Wales.

Recommendation 6:

Contracts between local authorities and care home providers should clearly specify any funding arrangements in relation to the provision of mobility support required in meeting assessed needs. Care Quality Commission inspections should review provider contracts with local authorities and report on whether these clearly specify all assessed mobility needs and the providers' responsibility in meeting these. Equivalent action should be taken in Scotland and Wales.

Recommendation 7:

The Care Quality Commission should revise their “Guidance about compliance: Essential standards of quality and safety” in relation to Regulation 19 of the Care Quality Commission (Registration) Regulations 2009, outcome 3 in order to make clear that any policies on charging for service transport or pooling the mobility component must be transparent and must provide choice and control to the individual. Equivalent action should be taken in Scotland and Wales.

15. Appendices

15.1 Appendix 1: terms of reference

The review should provide an independent report evaluating:

- how the mobility component of Disability Living Allowance (DLA) is being used by care home residents and the impact of loss of this benefit
- funding arrangements for meeting personal mobility needs as between local authorities and care home providers
- responsibilities of care home providers in relation to mobility needs of residents
- It should review existing guidance in relation to responsibilities of care home providers to meet the mobility needs of residents;
- Review what mobility needs are being met by social services through community care assessments and what is being left to be met by DLA;
- Review and comment on the degree of access to and control individuals have over DLA mobility payments to meet their mobility needs and/or the degree of control where money is used to buy an adapted car (inc. through the Motability scheme);
- Identify any areas of good or bad practice in relation to meeting the personal mobility needs of people living in residential care and make recommendations for associated guidance; and
- Make recommendations based on its findings for the future funding arrangements to meet mobility needs of care home residents.
- The review should seek to consult a wide range of external stakeholders, including disabled care home residents, family carers, care home providers, local authorities and independent experts/researchers. It should be overseen by an independent scrutiny group.

The review should present its report and recommendations by the end of October 2011.

15.2 Appendix 2: oral evidence sessions

The Review would like to thank the following individuals and organisations for providing oral evidence:

Time and date	Name	Role and organisation
Thursday 22nd September, morning	Sue Bott	Chief Executive, National Council for Independent Living (NCIL)
Thursday 22nd September, morning	Liz Sayce	Chief Executive, Royal Association for Disability Rights (RADAR)
Thursday 22nd September, afternoon	Hayley Jordan	Co-Chair, Disability Benefits Consortium (DBC) Policy Group
Thursday 22nd September, afternoon	Ruth Scott	Director, Policy & Campaigns, Scope and Chair, Disability Charities Consortium (DCC) Policy Group
Thursday 22nd September, afternoon	Neil Coyle	Director of Policy, Disability Alliance
Thursday 22nd September, afternoon	Laura Courtney	Campaigns Manager, Every Disabled Child Matters (EDCM)
Friday 23rd September, morning	Anne Price	Director, Education and Life Skills, David Lewis College and Vice-Chair of the National Association of Specialist Colleges (NATSPEC)
Friday 23rd September, morning	Marianne Selby-Boothroyd	Director of Development, Certitude
Friday 23rd September, morning	Natasha Kolicic	Service Manager, National Autistic Society (NAS)
Friday 23rd September, afternoon	Peter Hay	President, Association of Directors of Adult Social Services (ADASS) and on behalf of the Local Government Association
Monday 26 th September, all day	Disabled people living in residential care services in and around Bristol	
Tuesday 27 th September, evening	Epilepsy Society, Gerrards Cross, staff and residents	
Monday 10th October, afternoon	Dame Anne Begg MP	Chair, Work and Pensions Select Committee
Monday 10th October, afternoon	Dame Philippa Russell	Chair, Standing Commission on Carers

All sessions were recorded and transcribed before being analysed by the Review secretariat and an independent researcher.

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