

DLA mobility: sorting the facts from the fiction

The removal of DLA/PIP mobility component from people living in state-funded residential care



This report is endorsed by



Executive summary

We agree with the Government's commitment to social justice for disabled people and in particular the focus on personalisation and increasing independence for disabled people.

However, the removal of the mobility component of the Disability Living Allowance (DLA), soon to become Personal Independence Payment (PIP) from people living in residential care will directly undermine this commitment. It is extremely positive that the Government has said it will review how personal mobility needs are funded and we urge the Government to listen to disabled people, disability organisations, social care providers, local government and the Department for Work and Pension's own advisory committee, all of whom agree that this change would have a hugely negative impact on disabled people's independence and should not go ahead.

DLA mobility component provides absolutely vital support to many disabled people in residential care. It reduces their dependence on their care provider and directly gives them the means that they need to help meet the additional costs that they can face in getting out and about.

We are particularly concerned about the Government's continuing shift in rationale for this cut and the lack of supporting evidence. So far the Government has presented eight different arguments for the removal of DLA/PIP mobility from people living in residential care:

1. The responsibility for mobility / transport costs should be met by the care home provider
2. DLA mobility is being misused and needs reforming
3. DLA mobility is being used to purchase wheelchairs when this cost should be met by the NHS Wheelchair Service
4. The change will align the rules for people living in residential care with people in hospital
5. There is an overlap in transport provision for disabled people. Schemes such as dial-a-ride provide for the transport needs of individuals with a disability
6. Local authorities should be assessing and meeting personal mobility needs
7. Local authorities' contracts with care homes should cover personal mobility needs
8. People in NHS funded residential care do not receive DLA mobility

This report seeks to address each of these arguments and remove the confusion around responsibility for meeting personal mobility needs and the purpose of DLA/PIP mobility.

If the Government is concerned that greater clarity is needed we would welcome the opportunity to work with them on drafting clear guidance establishing who is responsible for meeting individuals' mobility costs and the role of DLA/PIP mobility.

Background

The 2010 Spending Review announced that from October 2012 the Government will no longer pay the mobility component of DLA to disabled people living in residential care, unless they are self-funders. More recently, the Government has agreed to

review the current situation and have delayed the introduction of the change until March 2013 when PIP will be introduced. However, the Welfare Reform Bill still contains a measure to give Government the power to remove the mobility component of PIP from people living in residential care.

In January 2011, 27 organisations, including disability charities and care home providers produced a report *Don't limit mobility*¹, to challenge the Government's proposal. This report was endorsed by the Association of Directors of Adult Social Services (ADASS) and addressed the three key justifications for removing DLA mobility from people living in residential care being presented by Government at the time.

Since the publication of *Don't limit mobility* the Government has provided a number of additional justifications for the proposal. This briefing attempts to address all eight of the Government's arguments to date and to show that none of them justify the removal of DLA/PIP mobility from people living in residential care.

¹ See: <http://www.mencap.org.uk/document.asp?id=20622>

RATIONALE 1: The responsibility for mobility / transport costs should be met by the care home provider

The rationale

The Government has stated that care homes are obliged to support disabled people's 'independence' as part of registering to provide a service and that this is outlined in legislation and guidance. As a result, therefore, the Government has said that there is no need to deliver support through the DLA/PIP mobility component.

What are the obligations of care homes?

The following sections from related guidance and legislation are what we believe the Government is referring to, although this has not been specified:

Regulation 17 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010, part 1 states that residential services must "so far as reasonably practicable, make suitable arrangements to ... provide appropriate opportunities, encouragement and support to service users in relation to promoting their autonomy, independence and community involvement".

CQC Guidance² in relation to Regulation 17 states that to comply with the regulations, residential services must "Encourage and enable people who use services to be an active part of their community in appropriate settings." This requirement is monitored by the Care Quality Commission (CQC). The guidance further states that a care home provider should: "so far as reasonably practicable, make suitable arrangements to ensure - a) the dignity, privacy and independence of service users" and that registered homes need to: "provide appropriate opportunities, encouragement and support to service users in relation to promoting their autonomy, independence and community involvement".

The fundamental issue

- If the care home is obliged as part of their registration requirements, rather than as part of contracts with local authorities or individuals to support disabled people's independence, this obligation would also apply to self-funders, who, under the same proposal, will not lose their mobility component of DLA/PIP.
- Related legislation and guidance make no specific reference to mobility or transport needs.
- While guidance places a responsibility on the provider to support services users in relation to 'promoting their autonomy, independence and community involvement', it contains nothing about how this is paid for or who is responsible for providing the funding to ensure this, nor does it provide a definition of what 'promoting' might include in this context.
- Care homes meet their obligation to support residents' independence partly by supporting people to use their DLA mobility. For example, a report into personalisation produced by the social care regulator in 2009 offered a 'good practice' example of how best care homes could support residents by providing options for residents to use their DLA mobility, including by pooling a percentage of DLA to pay for shared transport.³

² CQC: *Guidance about compliance: Essential standards of quality and safety*, March 2010

³ CSCI, 'Putting People First: Equality and Diversity Matters 3', February 2009, http://www.cqc.org.uk/db/documents/22275_proof_QISC_3.pdf

- The CQC guidance about compliance also states that “people who use services receive care, treatment and support where clear procedures are followed... The choices of people who use services are respected and accommodated unless: it would not be reasonable to expect the service to have the resources needed to achieve the choice”.
- This guidance is not contract terms. Rather, it provides evidence to both the service commissioner and service regulator that regulations are being complied with.
- The Department for Work and Pensions has stated that local authorities can take legal action to ensure care homes support personal mobility, but the guidance does not provide a legal requirement. Further, as extracts from local authority service specifications in *Don't limit mobility* show, contracts specifically state no obligation on the provider for transport / mobility costs, citing them as the responsibility of the service user and not the purchaser (local authority) or the provider (care home).
- Disabled people in residential care face additional costs in getting about in the same way as any other disabled person, and they currently have DLA mobility to help them meet those costs. Care homes are not provided with the resources to cover every accessible taxi journey that a resident may want to take, or to purchase an additional sports wheelchair, or an adapted vehicle for each resident, and the government has not proposed offering any more resources to cover this. Even if additional funding was provided it would mean that residents would become more dependent on the service, and less independent – the reverse of the Government’s stated policy intention.

RATIONALE 2: DLA mobility is being misused and needs reforming

The rationale

The Government has stated that there are clear examples of ‘misuse’ of DLA mobility. In particular, the Government has objected to residents pooling their money – for example, to buy a shared vehicle, or using their money to pay to use residents’ vehicles for non-essential outings, arguing that the care home should be providing transport. The Government has also expressed concern that sometimes it is a family member who has care of an adapted vehicle and that the individual only benefits on occasion when a family member comes to visit.

What is ‘appropriate’ usage?

The strength of DLA, and the same will apply to PIP, is that it gives the individual control over how it is spent, meaning it can be used in a wide variety of ways.

The fundamental issue

- The Government has cited some anecdotal evidence of bad practice. However, such claims need to be backed up with substantive research. If an issue is identified, it needs to be addressed through the assessment/ reassessment process for DLA/PIP and put right. Such examples of bad practice cannot be a good reason to simply remove DLA/PIP mobility from all residents, but rather point to issues around the administration of DLA/PIP.
- Residents do sometimes choose to pool their DLA and buy a shared vehicle. However, this is an example of individuals choosing to pool their money as the most effective use of their DLA. By pooling some of their DLA they can benefit from a shared vehicle whilst also having money remaining to meet other

mobility needs. Further, such an example should not assume an ‘obligation’ by the provider on the resident if the individual can choose to ‘opt out’ of this arrangement.

- Residents also choose to pay services for non-essential journeys. Services receive funding only for travel that meets an individual’s assessed needs, for example to a medical appointment. However, charges levied for non-essential journeys are typically significantly lower than equivalent taxi charges and enable individuals to maximise the benefit of their DLA.
- Families do sometimes keep the adapted car used to take a relative out on visits or away on holiday if an individual cannot drive it themselves. What is important is that it is a vehicle dedicated to meeting that individual’s mobility needs and they have decided that their own car is the most effective means of meeting those needs. There are also clear rules to ensure that cars obtained through the Motability scheme, which many people use their DLA mobility to fund, are always used for the benefit of the individual disabled person, and not for the personal benefit of a named driver. If there are any examples of the system being misused then it is of course right that these are acted upon – but removing people in residential care’s means of accessing an adapted car cannot be the right response.
- The key issue must be about the choice of the individual and the support being provided to the individual to understand their options and to make informed decisions.
- There are many illustrations of good practice by providers. For example, residents who have access to advocates who help them to understand the different options available to them and what the financial consequences might be.

RATIONALE 3: DLA mobility is being used to purchase wheelchairs when this cost should be met by the NHS Wheelchair Service

The rationale

The Government has argued that all wheelchair needs should be met by the NHS Wheelchair Service.

What does the NHS provide?

Provision of wheelchairs comes under the National Health Service Act (2006). Schedule one of the Act states that “the Secretary of State may provide vehicles (including wheelchairs) for persons appearing to him to be persons who have a physical impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities”. It further states that “the Secretary of State may (a) adapt the vehicle to make it suitable for the circumstances of the person in question, (b) maintain and repair the vehicle”.

The Health and Social Care Bill proposes to amend Schedule 1 to transfer these responsibilities from the Secretary of State to commissioning consortia. Thus, the Bill proposes that “a commissioning consortium may make arrangements for the provision of [vehicles (including wheelchairs) for] persons for whom the consortium has responsibility and who appear to it to have a physical impairment [which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities]”. It further states that “the commissioning consortium may make

arrangements for (a) the adaptation of [the vehicle to make it suitable for the circumstances of the person in question], (b) maintenance and repair of [the vehicle]”.

The fundamental issue

- Legal requirements placed on the Wheelchair Service are unspecific and do not reflect the importance of choice and personalisation.
- There are wide variations in what Wheelchair Services will provide. For example, neither the Salford Wheelchair Service nor the Hertfordshire Wheelchair service will provide powered wheelchairs solely for outdoor use whilst at the Roehampton Wheelchair Service Electrically Powered Indoor Wheelchairs “are not usually issued to clients living in residential or nursing homes.”
- The responsibility for the Wheelchair Service passing to commissioning consortia can be expected to lead to even greater variation in provision.
- NHS provision of wheelchairs focuses on the medical model of disability and on mobility around the home: “Eligibility criteria focus primarily on addressing basic mobility and postural needs. As such they are largely fixed within a medical model that relates to functional impairment, the physical and medical needs of an individual rather than the barriers to independence and whole lifestyle needs that they face.”⁴ This is in contrast to DLA mobility which is often used to enable people to access the wider community.
- There is no requirement for the Wheelchair Service to meet all an individual’s mobility needs.
- Disabled people should have choice in terms of mobility support – in order to enjoy full independence a person may prefer a specific outdoor scooter which can cover longer distances, for example. Or someone with a visual impairment may find that a particular technological option such as an obstacle detector will support their independence. Such options may not be available through statutory services and without DLA mobility people in residential care will simply be left isolated and without any resources to access the support that they need.

RATIONALE 4: The change will align the rules for people living in residential care with people in hospital

The rationale

The Prime Minister has responded four times during Prime Minister’s Question Time on the issue of the removal of the DLA mobility component from people in residential care. In all responses, he has stated that “our intention is very clear: there should be a similar approach for people who are in hospital and for people who are in residential care homes. That is what we intend to do, and I will make sure that it happens.”⁵

⁴ Care Services Improvement Partnership (2006) Out and about: Wheelchairs as part of a whole systems approach to independence.

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4140066.pdf

⁵ Prime Minister’s Question Time, 12th January 2011:

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110112/debtext/110112-0001.htm>

See also:

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101124/debtext/101124-0001.htm>

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110126/debtext/110126-0001.htm#11012654001017>

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110216/debtext/110216-0001.htm#11021651001597>

Does this align circumstances?

People in residential care receive DLA mobility whilst an individual staying in hospital does not get DLA mobility unless it is being used to pay for their Motability car (to prevent them losing their car during their hospital stay).

The fundamental issue

- It is entirely inappropriate to compare those who are unwell in hospital for a particular period of time, with those who have been living in residential care for most of their lives. It is their home and they are not patients. They are not ill. They are disabled; a group of people the Government has stated they are committed to increasing their independence and participation in society. It is essential, therefore, that they are supported appropriately to get out and about into the community.
- People living in residential care have the same expectations of an independent personal life as everyone else.

RATIONALE 5: There is an overlap in transport provision for disabled people. Schemes such as dial-a-ride provide for the transport needs of individuals with a disability

The rationale

The Government has stated that many disabled people access transport provision through locally run schemes, such as dial-a-ride, which suggests an overlap in funding for transport / mobility provision where people are also receiving the mobility component of DLA.

How do such schemes provide for disabled people?

Many local authorities offer door-to-door transport schemes (like dial-a-ride) for people with restricted mobility. Some local authorities will charge for these services, and operate different eligibility criteria for membership. Often eligibility for dial-a-ride services – or similar schemes – is based on an individual getting the higher rate mobility component of DLA. Similarly, rules around schemes like Shopmobility vary across the country, with some offering free services, some requiring membership fees and some including daily or weekly hire charges.

The fundamental issue

- DLA/PIP mobility gives absolute control. Residents can use DLA at a moment's notice; schemes like dial-a-ride cannot replace this flexibility. For example, the London dial-a-ride scheme guidance states that “dial-a-ride may not be able to accommodate all of your requests, particularly if they are time specific”.⁶
- Local authority run transport schemes are locally determined and vary enormously, both in availability and eligibility for membership. Some local authorities will charge an annual membership fee; others will charge a fixed fare for each journey. Many disabled people will use their DLA mobility to pay for this provision.
- Many local authorities are cutting back on services like dial-a-ride.

⁶ London Dial-a-Ride, your guide to Dial-a-Ride, Transport for London

The following justifications for the changes were addressed in the *Don't Limit Mobility* report:

RATIONALE 6: Local authorities should be assessing and meeting personal mobility needs

The rationale

“Local authorities have a duty to carry out an assessment of need for community care services for individuals. Based on that assessment a decision is made as to which of those assessed needs should be met by specific services.”

Minister for Disabled People, Maria Miller MP, House of Commons (written answer, 21 December 2010)

How does the local authority assess need?

Local authority services are designed to meet only needs which fall within a set eligibility framework. This identifies four bands of need: low, moderate, substantial and critical, and the majority of councils will only fund substantial and critical needs. Based on each local authority's policy around which bands are regarded as eligible for services, it is determined which needs will be met by the local authority.⁷ Therefore, an individual may be eligible for DLA/PIP mobility component but not be eligible for support according to local authority criteria.

Furthermore, even when mobility needs are factored into care packages, local authority contracts with care homes cover activities of daily living which include providing access to doctors, dentists and local services such as libraries and banks. They do not factor in the costs of individuals' personal mobility needs, for example, a navigational aid or sports wheelchair or the cost of going out for a social event.

The fundamental issue

- In its interpretation of assessed need, a local authority does not usually include activities like going to the cinema, visiting a leisure facility or meeting with friends and family.
- We know from the evidence that often when funding for transport is included within an individual's care package, this is only to cover the costs of travel that are directly related to their specific care needs (for example regular attendance at a day centre).
- The key question is about whether or not an individual's assessed needs will meet the FACS criteria.⁸ While an individual's personal care needs may be regarded as critical, this may not apply to an individual's mobility or transport needs.
- We know that many local authorities will only fund needs that are critical and substantial. The overwhelming majority of those with moderate and low needs are not provided for. This means that even if local authorities agree that an individual has personal mobility needs, these needs may still not fall within the

⁷ In 2007/08, 74% of local authorities set eligibility criteria at 'substantial' or 'critical' only – see *Cutting the Cake Fairly: CSCI review of eligibility criteria for social care (October 2008)*

⁸ '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.

right criteria to receive funding. This would mean that people with lower needs but living outside of residential care, whose support for personal mobility continues to be provided through DLA/PIP, could receive support with personal mobility denied to people living in residential care, creating a two tier system.

- This rationale contradicts the more recent argument that mobility costs should be met by the care provider (see rationale 1).

RATIONALE 7: Local authorities' contracts with care homes should cover personal mobility needs

The rationale

“Local authorities’ contracts with care homes will cover services to meet a resident’s assessed needs. These will cover activities of daily living which may include providing access to doctors, dentists and local services such as libraries and banks. Local authorities should also take into account the resident’s emotional and social needs as part of the assessment.”

Minister for Disabled People, Maria Miller MP, House of Commons (written answer, 16 November 2010)

What are the arrangements between the local authority and the care home?

The formal arrangements between a local authority and care home may or may not specifically address the transport needs of the individual. Contracts tend to be costed against the eligible needs identified by the local authority through the community care assessment. In many cases, when an individual is being assessed by a local authority for a care package all of the benefits to which they are entitled are taken into account. Whatever the formal arrangement, in practice, the provision of 24-hour residential care has by custom and practice covered personal care, food and limited activities in the home. It has not generally covered activities outside the home apart from day services.

The fundamental issue

- Contracts are costed against the needs identified by the local authority through the community care assessment. If personal mobility needs are not covered by this assessment (see rationale 5) then there will be no attached funding in the contract.
- With increased pressures on local government, contracts are unlikely to include funding for anything beyond “activities of daily living”.
- If local authorities cannot make up this funding shortfall, the responsibility will fall to the care home provider.
- Care home providers are already faced with considerable increases in costs as a result of inflation – which is considerably higher than the Retail Price Index (RPI) – without the added financial burden of having to provide for additional mobility costs.
- Existing service contracts are under enormous cost reduction pressures. Voluntary care home providers are not budgeting for any growth in fees income in 2011/12, but rather the reverse.

RATIONALE 8: People in NHS funded residential care do not receive DLA mobility

The rationale

“The arrangements are further confused by different funding streams ... For example, NHS-funded individuals in residential care do not receive the DLA mobility component, while those funded by local authorities do. If we want to be fair – not only to disabled people, but to taxpayers – we have to tackle the gaps and overlaps and ensure that everyone gets access to the mobility they need.”

Minister for Disabled People, Maria Miller MP, Westminster Hall (debate, 30 November 2010)

What is the situation for NHS-funded individuals?

Where an individual is funded by NHS continuing care, it is correct that they will not be eligible for DLA/PIP mobility. This is because they are regarded as patients under related guidance and regulations, ie the person is seen as a patient where the NHS is providing nursing services, and these nursing needs are more than incidental and ancillary to other care needs. In these cases, the NHS is providing a round-the-clock all-encompassing package of care and support. Where someone is part-funded by the NHS and the local authority (whether or not the service is commissioned by the NHS, the local authority or jointly), they are not regarded as a patient and are therefore eligible for the DLA/PIP mobility component.

The fundamental issue

- It is unusual for an individual receiving NHS funded care to live in a residential care home. In some cases nursing care is provided, but provided this is ancillary to the main purposes of the home the individual remains eligible for the DLA mobility component.
- There are some homes that are dual registered (residential and nursing homes) where there could be a small number of people who are fully funded by the NHS living with people who are funded by the local authority. Therefore there could be a minority of cases where in the same care home some residents are getting the mobility component of DLA and some are not.
- Also, NHS continuing care is not means tested. This means that residents whose care is funded by the NHS do not have to pay towards their care whilst residents whose care is funded by the local authority have their income taken to pay for their care and are left with just the £22 per week Personal Expenses Allowance.
- The assumption that the measure will end an anomaly ‘whereby two state-funded residents with similar needs who are placed in the same care home can be treated differently according to whether they are funded through the NHS or local authority’ is inaccurate in the vast majority of cases.
- Therefore, to try to tackle this limited anomaly, where a very small minority are not getting the mobility component of DLA, by removing it for the majority, is wrong. A fairer way would be to ensure that all residents are receiving the mobility component of DLA/PIP.

Conclusion

The Government has said that the removal of DLA mobility from people living in residential care is not a cut, but rather is about making sure there is clarity in who has responsibility to provide transport on both a day-to-day basis and to fund other transport and mobility needs that support disabled people to get out and about in the community.

DLA mobility component provides absolutely vital support for many disabled people in residential care. Local authority charging rules mean that almost all of an individual's income can be taken to meet care costs, leaving many people with just the Personal Expenses Allowance of £22 per week, and their DLA mobility component. Taking away DLA/PIP, mobility component will leave people unable to afford independent travel and solely reliant on the care home. However, as local authorities are not required to meet personal mobility needs there is no funding for residential homes to meet the shortfall that will be left by the removal of DLA/PIP mobility.

We welcome the commitment to review the funding of personal mobility for people living in residential care. The Government has said that there is a need for greater clarity as to where responsibility lies for meeting personal mobility needs. We hope this report helps provide that clarity and we would welcome the opportunity to work with the Government on producing guidance around this.

People living in residential care have personal mobility needs the same as people who do not live in residential care. We strongly believe that cutting DLA/PIP mobility component for this group will undo decades of progress and lead to the physical and social isolation of disabled people. Furthermore, it signals an alarming reversal of the Government's commitment to promoting social justice for disabled people and the focus that has been given to increasing independence, participation and employment opportunities.

Find out more

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