‘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

A report submitted to Capability Scotland and the Margaret Blackwood Housing Association by:

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‘HOW AM I GOING TO PUT FLOWERS ON MY DAD’S GRAVE?’ HOW CARE HOME RESIDENTS USE THE MOBILITY ELEMENT OF THEIR DISABILITY LIVING ALLOWANCE.

Summary.

As part of the Comprehensive Spending Review announced in October 2010, the Conservative and Liberal Democrat coalition announced changes to a range of disability entitlements. One such change included the removal of entitlement to the mobility element of the Disability Living Allowance (DLA) from those living in residential care homes. This report, which is based on interviews with over 50 adults living in residential care homes across Scotland, their families and key workers describes the impact that this change will have.

Key points.

– All participants spent the mobility component in full over a 12-month period. No accruals were possible.

– All participants were aware of receiving the mobility component and had a full say in how this was spent.

– Many were unable to save up their mobility component to pay for holidays or longer trips away from the care home because their DLA income only just met their day-to-day activities.

– Participants depended on the mobility component to see family including their children, partners, parents and other relatives.

– In many cases, trips to see friends and family had to be subsidised because the mobility component was not sufficient.

– The mobility needs of the participants meant that most forms of transport were inaccessible.

– Full access to health and social care services currently depend on the mobility component of the DLA.

– Under current funding arrangements, general practitioners were not able to provide all residents care through home visits.

– Care homes were facing up to a 20% cut in the funds available to provide care and support.
Introduction.

In October 2010, the Chancellor of the Exchequer, George Osborne, announced as part of the comprehensive spending review (CSR) that, after four weeks living in a residential care home, state-funded residents would have their mobility component of their Disability Living Allowance (DLA) removed. The Government justified this change on two grounds; firstly, that it would bring residents of care homes in line with hospital in-patients and, secondly, individual residents did not need the DLA mobility component because their needs were already being met by either local authority funding for transport for care home residents or by the care homes themselves. Both these assumptions have been challenged by disabled people’s organisations.

This research was commissioned by Capability Scotland and Margaret Blackwood Housing Association.

The aims of the study were to:

- assess the use care home residents made of their DLA mobility component;
- make recommendations on any action needed.

Methods.

The project used a range of qualitative research methods including focus groups, face-to-face individual interviews and telephone interviews. In total, we spoke to over 50 care home residents, to some of their families, to managers of care homes and support workers in those homes, and to health and social care professionals.

Findings.

Overall, we found that care home residents used their DLA support on a range of activities. Access to transport was funded by each person’s mobility element and was spent on:

- their own vehicle, which gave optimum freedom to the individual in terms of access to transport;
- a shared vehicle (vehicles were shared between 2-300 adults), through pooling the money with others;
- private taxis, which cost a great deal and were rarely accessible;
- albeit rarely, public transport, which was inaccessible to the majority of individuals;
- A small number of residents used the mobility element of their DLA to fund powered wheelchairs.
- Participants depended on the mobility component to see family, including their children, partners, parents and other relatives.
This transport was also used for a variety of other activities. These included:

- college and other educational activities;
- church;
- social and political clubs;
- football matches;
- the library;
- shopping;
- museums;
- trips into the countryside;
- bowling;
- cinema;
- art galleries;
- holidays.

Without access to this money, all these social activities would be denied to care home residents.

The money was also used for hospital visits, to go to the GP, chiropodist, podiatrist, physiotherapist or other health care professional. Again, without this support, access to these important health care services would not be possible.

**Conclusion.**

Care home residents use the mobility element of their DLA to help fund a wide range of activities and, if this payment is removed, their opportunities for participation in the mainstream will be greatly reduced. Without access to this money, many residents will no longer be able to leave their homes, get out and about, visit health care providers, go shopping, visit their family or have their family visit them, go to clubs and participate in local organisations or take part in leisure activities enjoyed by their peers. This money is very important in helping promote independence and autonomy and in ensuring that care home residents are able to exercise choice in their lives. There is a real danger that, if it is withdrawn, we will see a return to the days when care home residents did not leave their homes and spent all their lives living within the confines of their institution. Many of the older residents we talked to could remember those days and were genuinely scared at the possibility that they may have to live under such conditions again.

One of the great strengths of the DLA as it is currently formulated is that it allows disabled people choice in how the money is spent and it plays a crucial role in helping people stay independent or achieve independence. Many people living in care homes value this and want to live as independently as they can for as long as possible. Some residents also saw a future beyond the home and were planning for a life outside of the residential care home setting. This desire was, in part, stimulated by taking part in activities outside of the home and, through this, realizing that living independently in their own homes was a possibility. Without the financial support afforded by the mobility element of the DLA, this is unlikely to happen.
Further, not only will this change impact on care resident’s ability to access health and social care services and affect the quality of care and support they receive, it will also affect those services themselves. For example, unless alternative funding streams are introduced, more stress will be placed on the patient transport service and the role of general practitioners in delivering care to residents will have to be re-examined.

Given this, it is not surprising that the initial proposal to remove the mobility element of the DLA from residents in registered care was met with such hostility by the large number of organisations who work with disabled people and from care home residents themselves, as the recently published response to the public consultation on reforms to DLA testifies1. An outcome of this consultation has been a commitment to review the plans to withdraw this funding:

“The Government has listened to the strong concerns raised by individuals and organisations about the Spending Review proposal to withdraw the DLA mobility component from people in residential care. The Government will not now introduce this measure as planned in October 2012. We are both reviewing existing and gathering further evidence to inform how best to proceed. Meeting the mobility needs of people in residential care will now be considered as part of the wider reform of DLA. The Government is committed to ensuring that residents of care homes are able to get out and about, and is therefore looking to remove overlaps in funding, not mobility.2

Our hope is that this report can be fed into this review and that the data collected can help the UK Government as it develops its plans to reform the DLA. At the outset of this review process Maria Miller, Parliamentary Under Secretary of State and Minister for Disabled People, in the ministerial forward to the public consultation document that opened the review stated:

“We are steadfast in our support for the principles of DLA, as a non-means-tested cash benefit contributing to the extra costs incurred by disabled people. However, we need to ensure that the benefit reflects the needs of disabled people today, rather than in the 1990s.”3

The data collected as part of this review will provide the Under Secretary of State with the information she requires to ensure that the review fully meets the needs of care home residents and that future plans do not see the introduction of an inferior, unreasonable and unfair system and that they retain the mobility component in the new PIP for people in residential care homes.

2 Ibid P.6
It is also our hope that the Scottish Government will be able to take heed of the evidence gathered about the extensive use of the mobility component of DLA by people in care homes and that they are able to exert pressure on their Westminster counterparts to ensure that residents of care homes are not disadvantaged by any future changes in the support they receive.
Disability Living Allowance and the Comprehensive Spending Review – The Background.

Disability Living Allowance (DLA) is a non-taxable, non-means tested universal benefit for people who become disabled before the age of 65. It was first introduced in the UK in 1992 when it replaced and extended the Attendance Allowance and Mobility Allowance. Together with the Disability Working Allowance, which came into effect at the same time, these benefits marked a change in social security policy and were the first benefits to be aimed at disabled people in work⁴.

The aim of the DLA was to help disabled people meet the extra costs associated with their disabilities and it was introduced in response to the 1990 White Paper, *The Way Ahead – Benefits for Disabled People*. It followed nearly thirty years of campaigning by disability organisations as well as ten years of Government deliberations⁵. The White Paper was produced in direct response to a series of surveys conducted by the Office of Population, Censuses and Surveys (OPCS) of disabled people in Great Britain published between 1985 and 1989⁶, which all pointed to the financial hardships experienced by those who were disabled⁷. Its introduction marked a shift in benefit policy towards providing disabled people with the support required to live lives in the mainstream.

The DLA has two components; a care component and a mobility component. To qualify for the mobility element, an individual must have a mobility impairment that is severe enough for them to have the following walking difficulties, even when wearing or using an aid or equipment:

- unable or virtually unable to walk without severe discomfort, or at risk of endangering or causing deterioration to health by making the effort to walk;

- have no feet or legs;

- assessed to be both 100 per cent disabled because of loss of eyesight and not less than 80 per cent disabled because of deafness and to help when out of doors;

- severely mentally impaired, with severe behavioural problems and qualify for the highest rate of care component;

- need guidance or supervision most of the time from another person when walking out of doors in unfamiliar places.⁸

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⁵ Ibid
⁶ OPCS Surveys of Disability in Great Britain, Reports 1-6 1988-89
⁸ http://www.direct.gov.uk/en/disabledpeople/financialsupport/dg_10011731
It is currently paid at two rates: A lower rate of £18.95 per week is payable if the individual needs guidance or supervision out of doors. The higher rate of £49.85 per week is payable if the individual has more severe walking difficulties.

People use their mobility element for a variety of reasons including paying for cars and other forms of transport and for lightweight or powered wheelchairs. It makes a vital contribution to their independence and their ability to participate in the mainstream of society. Without the mobility element, many disabled people would not be able to go out and meet friends, attend leisure centres, go shopping or, in many cases, go to work9.

In June 2010, the then recently elected UK Conservative/Liberal Democrat Coalition Government set in motion a Comprehensive Spending Review (CSR) which aimed to drastically cut the UK welfare budget. In October 2010, the results of the CSR were released and, in that, the Government detailed a range of proposals which aimed to secure substantial savings from DLA. First, the Government proposed the removal of entitlement to the mobility element of DLA to those living in residential care homes from 2012/13. Second, the Government proposed radical changes to the way that DLA is assessed, which will be introduced in 2013/14.

The change to entitlement to the mobility element of DLA for care home residents relates only to those who are in hospital, care home or similar institution for 28 days or more, and whose care and support is paid for through a public body. It is not known at this time how these time periods will be calculated; whether it will be continuous or cumulative. It is estimated that there are roughly 80,000 disabled people in the UK who will be affected and that this move will save £135m per year.

It is unclear yet as to whether or not children and young people will be affected by this change. The Government’s initial thoughts are that, for children and young people, the DLA Mobility component will stop following a period of 84 days for a child resident in a care home funded by a public body payment.

The thinking behind these changes is that the Government should not pay twice for the same service provision. In a written answer to Parliament on 2nd November 2010, Maria Miller MP, the Minister for Disabled People, stated that these changes should not affect care home residents because the contracts made by a Local Authority with a Care Home should:

“cover services to meet all a resident’s assessed needs, including any assessed mobility needs, so an individual’s care support and mobility needs should be met by residential care providers from social care funding. This measure will remove an overlap of public funds while ensuring that resources continue to be targeted at disabled people with the greatest needs.”

For this reason, people who fund their care wholly through their own funds are not affected by this ruling.

9 Disability benefits Consortium Do not Limit Mobility (2011)
http://www.disabilityalliance.org/dbcdontlimit.htm
These changes were met with widespread anger by disabled people and their organisations and there was a great deal of mobilisation of resources to challenge the proposed cuts. In February 2011, a consortium of organisations of and for disabled people published a report, *Don't limit mobility: The impact of the removal of the mobility component of Disability Living Allowance from adults and children living in state-funded residential care* which presented arguments to counter those above and presented evidence drawn from a survey to document how disabled people in residential care spent the mobility element of their DLA. On February 23rd, the Social Security Advisory Committee (SSAC), the UK advisory body on social security matters, published a response to these changes. In this report, the SSAC concluded:

"We consider that the proposal to remove the mobility component from people in residential care should not go ahead. This measure will substantially reduce the independence of disabled people who are being cared for in residential accommodation, which goes against the stated aim of the reform of DLA to support ‘disabled people to lead independent and active lives’.”

As a direct result of these and other campaigns, the Government announced a further review of the policy, pushing back implementation until 2013. In the Second Reading of the Welfare Bill on March 10th, 2010, Iain Duncan Smith, the Secretary of State for Work and Pensions, whilst accepting that there was a need to review the policy, would not guarantee that the benefit would be preserved. His only commitment was to ensure that any future benefit would provide the ‘amount necessary for people who are in residential care’.

In this report, we develop the earlier work by the Disability Benefits Consortium and use data collected through interviews with a range of care home residents, care home managers and other health and social care professionals to present data on how the mobility element of DLA is used by disabled people in Scotland and the impact that its removal will have on their quality of life. In so doing, our intention is to provide the Secretary of State with the information required to reconsider the proposed changes.

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12 http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110309/debtext/110309-0002.htm
Methods.

In preparing this report, we carried out a number of individual face-to-face interviews and focus groups and asked people how they spent their mobility element of DLA. We also asked them what the implications would be if that money were to be withdrawn. We talked to residents from a range of care homes across Scotland and included those run by not-for-profit organisations and the voluntary sector and those run by commercial organisations. The people we talked to had a variety of impairments including acquired brain injury, physical impairments, chronic illness and learning disabilities.

In total, nine care homes participated in this research. All in all, over 50 residents of care homes took part in either one-to-one interviews or focus groups. We also spoke to some of the residents’ family members as it quickly became apparent that this change would affect them as well as the disabled person themselves.

At each home, we also talked to at least one member of senior management who had some insight into the consequences of the cuts; in total, 21 staff members participated. The final group we talked to were health and social care professionals.

As is the norm with most qualitative social research, the identity of participants is being kept confidential. However, in order to avoid a sanitisation of their voices, pseudonyms have been provided.
Findings.

Introduction.

Despite having access to the mobility component of DLA, most individuals struggled to fund their transport needs on the current rate of £49.85 per week. What follows is an exploration of the uses of the mobility element of the DLA and the perceived consequences of its withdrawal. There was a great deal of emotional expression during the meetings, showing how vital the mobility component is. One participant said,

“I don’t think it’s right or fair. It’s not fair. What the f*%king hell are they going to do about it. I feel anger, I’m flipping livid.”

Mark.

Another participant argued,

"Time to fight back. We know what the background is. Terrible that they’re taking money off us, we have to stand up and be counted. Have to criticise the decisions that are being taken.”

Josh.

And,

"We’re not going to be still. We’re going to react to this."

Emma.

In this report, we present our findings thematically. The report begins with a review of how the mobility element is managed by care home residents. The largest section focuses on how vehicles are used, including an exploration of ordinary day-to-day use, keeping contact with family members, access to health care services and political representation.

The report continues by considering the psycho-emotional impact that these cuts could have. Very much related to this theme is the question of what happens after care. Many residents spoke about aspiring to independent living and this could be seriously threatened if cuts are made to the mobility component. The report moves on to consider access to mobility aids to show how the mobility element is used for more than just access to vehicles.

The report concludes with two themes that reflect more widely on the consequences of cuts to the mobility element. It is clear that these cuts will impact significantly on the capacity of care homes to meet Scotland’s National Care Standards. Finally, the report will consider the lack of options available to disabled people, or the organisations that support them, to access travel funds from other sources.
Management of the mobility element of DLA.

This section reviews how the mobility element of DLA is used by individuals in residential care homes. There was a move towards residents owning their own ‘motability’ car. Most participants aspired to this, though only a few were able to manage the cost. Therefore, most participants had to rely on communally owned vehicles which they could contribute to using their mobility component. By pooling their resources, the residents were able to afford a larger vehicle than if they bought it independently. This is crucial because many disabled people need a larger car to accommodate their wheelchair and the other equipment they need to carry with them.

Access to transport was funded by each person’s mobility element. Money was either spent on:

- their own vehicle, giving optimum freedom to the individual in terms of access to transport;
- a shared vehicle (vehicles were shared between 2-300 adults), through pooling the money with others;
- private taxis, which cost a great deal and were rarely accessible;
- albeit rarely, public transport, which was inaccessible to the majority of individuals.

Where participants had access only to vehicles run for the care home rather than for them individually, there was a significant limitation on their freedom. One manager commented,

"With the mini bus, people have to fall in and do what we want. It is re-introducing institutional living.”

Derek.

In almost all cases, the mobility element was provided directly to each participant, who had their own bank account and full control over budgeting. Several people had accounts managed by family or by the care home manager. In no case was the mobility element allowed to accrue unless a specific trip or purchase of a particular mobility aid was being saved for. This practice falls completely within the original terms of the DLA. Over a 12-month period, the mobility element was spent in full by each disabled person we spoke to.

There was awareness among some of the people we talked to that, if their home de-registered, then they would be categorised as living independently and would not be susceptible to the proposed cuts. Amy lived in a small care home that was split into flats. Within the same built complex lived a man who had the same level of support needs but who lived in a private residential house,

"We are very aware of what they are trying to do. We all know about it and we spoke about it at our users group. We are very cross. It’s not fair, it is unfair to target those that live in registered care homes.”

Amy.
Use of vehicles - everyday use.

In this section, we consider the ways that participants use transport on a day-to-day basis. Many tasks may appear very ordinary. However, practices like going to buy a newspaper allowed participants to actively participate in their local communities. The freedom to live in ordinary ways is compromised where residents cannot afford their own transport but have to share.

As discussed above, when the mobility element is used to fund a bus, access to the transport is limited, both in terms of the time it is available for use and in terms of who is able to decide the destination. At one care home, use of the bus is restricted to between 10am and 3pm on weekdays. This is because of the staffing levels required. Taxis can be used in the evening and at the weekend but, at three homes, most participants said that taxis are inaccessible and too expensive. Part of the issue is that these homes are situated five miles away from the nearest taxi company, so the pick-up fare alone is significant.

At the same three homes, public transport is limited to just one public bus that runs hourly but not reliably. In the past, bus drivers have refused to get out of their cab to help participants on and off the bus, leaving them stranded. This has left a legacy of fear among the residents who are unwilling to risk the re-occurrence of this incident. In the other four homes that have rural locations, local buses do not have drop floors, or are not provided after 6pm. Only two of the nine homes are based in an urban location, the others are in rural towns and villages.

Trains are similarly inaccessible. Most people interviewed do not live near a train station. Of those that do, they live near a station that is not accessible to wheelchair users. Murray had tried to use a train to get to Edinburgh, but despite phoning ahead to ask for ramps, found no ramps to get onto the train and no ramps for the journey back. He had to resort to an expensive, and un-budgeted for, taxi journey home.

Everyday use of transport also includes social trips to concerts. Many participants were enthusiastic about these trips. An obvious statement, perhaps, but one participant said,

"I feel amazing listening to [live] music, feels like it's a blast. It's amazing because you never get that feeling at home. Would love to go clubbing but it's too expensive and they're up stairs."

Christopher.

Everyone in a focus group of 14 participants agreed that they wanted to go to clubs and experience night life. They were restricted by access to buildings but also the cost and availability of accessible taxis. This is more of a problem at 1am or 2am when fewer taxis operate. Here though, we have a group of young adults who are keen to participate in the activities of their peers and are excluded from doing so. The cap on the mobility element that currently exists is part of the problem. This is a group marginalised from experiences that the majority would consider a right. A further erosion of mobility funding would have a catastrophic impact on those that we talked to.
For the people we spoke to, other significant venues accessed by participants using their mobility element include:

- Social clubs, where friendships with people not living in the same care home can be maintained.
- Five participants we spoke to use their mobility element to go to Church. This freedom to worship was a central facet of their identity and a direct expression of their religious belief.
- College, where people not only learn but socialise and meet new people.

  "Going to college is very important. I got a good circle of friends, at my birthday I had people from college at the party, the car allows me to participate."

  Euan.

Not only is public transport inaccessible for the person, it often doesn’t take people where they want to go. One participant, who has a keen interest in reading and writing poetry, took a trip to Robert Burns’ house. Without her car, she would not have been able to make this trip. Such an excursion is integral to her identity as a poet, and as a Scot.

Other activities included:

- going to watch football matches;
- going to the library;
- clothes shopping;
- museums;
- trips into the Scottish countryside;
- bowling;
- cinema;
- art galleries.

Often participants cannot use the closest cinemas, swimming pools or bowling clubs because they are not as accessible as ones further afield. One care support worker said that the mobility element funding, as it stands, limits individuals’ exposure to activities,

  "Physical activities depend on finances but realistically the guys should be out every day but money prevents that. They get out once a week."

  Karen.

This degree of isolation is severe but not uncommon.
Access to health care services.

In this section, we will consider the ways in which the DLA mobility component is used to access health services. State support for disabled people has changed over recent decades from seeing people as passive patients to understanding the holistic needs of an empowered individual able to choose for themselves. Most people we spoke to were actively in control of their health care needs and were able to choose which health care professionals they consulted. This was an important issue for participants.

Of particular importance were visits to their general practitioner. Individuals living in the same home did not automatically use the same medical practice, showing a standard level of choice about which services and how services are accessed. This autonomy was of central importance to participants. They expressed real concern about being able to see their own doctor, someone who they had built a relationship with and who they trusted. The alternative of having home visits from doctors was not well received by individuals. They felt that their needs were rarely urgent in nature so they would be inappropriately using this service. Also, by using home visits, individuals believed that they would have less control over which doctor they saw and this was not considered acceptable. Given the sometimes complex health care needs of the people we spoke to, it does seem logical that someone experienced in their medical history is better able to provide efficient and relevant care.

"Sometimes the GP comes here but if you go to your doctor, you have to go out to the surgery. It’s not nice seeing a doctor that you don’t know. Even less choice and less control.”
Susan.

General practitioners were also quick to point out that they were not prepared to administer all the care and support that a care home resident may need on the basis of home visits. As one practice manager told us:

“We will not be able to take on these patients or that sort of support. We cannot visit patients in care homes. These are very heavy users of the service and we just couldn’t manage the level of care needed. We will not be able to manage this.”
General Practitioner Practice Manager.

Providing home visits for care home residents is not part of the GP contract, which states that visits to such homes should be based on clinical need and not convenience. The contract further states that there is an expectation that residents will go to the surgery when a medical consultation is required.

Visits to dentists are also paid for using the mobility element and, if a participant needed work in addition to regular check ups, then this would impact on their mobility element significantly. Because specialist equipment was required, most participants had to go out of their homes to visit their dentist. Two homes asked dentists in to provide basic check ups but, because of a lack of equipment, these were limited in scope.
A large proportion of respondents needed to attend health care appointments at hospitals. Those that had access to their own vehicle had access to the most convenient and cost-effective transport solution. Although patient transport could be requested, there were significant barriers to access:

- Buses did not often have the chair lifts needed.
- Some homes were too far from the hospital to be accommodated.
- Patient transport funding has been cut drastically and the service removed from some areas.

One participant had been to hospital for a 20 minute appointment but, because the patient transport they used was over an hour early, had to wait for over two hours to be picked up to go home, and sat on the bus for over two hours while others were dropped off first. Because of their support needs, this was unacceptable. Too long restrained in their wheelchair caused pain and fatigue. One participant reflected on a similar experience to this and described it as ‘traumatic’. In addition, some hospitals had made the decision to cancel appointments, not because the healthcare services were unavailable but because the patient transport service decided that they could not meet the travel needs of the participant on the day in question. So, here, funding cuts to transport are already impacting on how able residents are to access health care professionals.

Some participants had to fund their transport to visit physiotherapists and speech and language therapists. Access to these professionals is vital to reduce pain, optimise mobility and optimise communication. However, again, patient transport was rarely available and, if it was, it was problematic to use. One resident used his DLA to help fund physiotherapy, without which he would not be able to get out of the home and would be confined to his bed.

If a taxi is needed to get to an appointment, this can cost between £20 and £60 each way. Hence more than a fortnight’s mobility element can be used to get to a single hospital appointment. For some, hospital appointments were a routine part of their medical support. One participant had to attend hospital for cancer treatment, which illustrates how fundamentally crucial access to hospital care is.

**Access to family life.**

Access to family life is a human right protected by the United Nations, the European Court of Human Rights and features strongly in UK legislation. Yet many participants were unable to regularly and frequently visit their children, their partners, their parents or other family members. This section reviews some of the accounts we heard.
Almost all participants used the mobility element to see relatives. In some cases, this involved participants visiting ageing parents unable to physically manage, or financially afford, the trip to the care home. These trips home were vital to maintain family links with loved ones and also provided opportunities for residents to return to communities that they called ‘home’. In some cases, this was exacerbated by a legacy of decisions taken to move people away from their communities and to homes thought to offer a specialist service. For those who have lost parents, siblings become an important tie to their home communities. Euan spoke about wanting to visit his mum, who still lives in the same home that he was born in, and visiting his sister who helps him put flowers on his dad’s grave once a year.

Many individuals fell into a trap of being unable to travel home because home was too far away. One woman had been moved up from Devon and had not been able to visit home for over 32 years, until she finally managed to save up for the trip last year. Another went to stay with his daughter in North Wales every Christmas but the mobility element was insufficient to pay for this and so he relied on his daughter funding the trip.

For those individuals who had children, they were mostly grown up but there were several cases where the children were under the age of 18. One participant’s daughter was at University and so had no money, herself, to visit her Mum. Therefore both relied on the mobility element in order to be able to spend time together. Restrictions in travel severely impacted on the participant’s human right to a family life. One manager argued,

"Those with children are often those with the most restricted mobility and the family visits are so important."
Derek.

Because of the need to take additional equipment, one person had calculated that it would cost them £600 to travel each way to their family home in Elgin, a distance of just 86 miles from their residential care home. This is because they would have to hire a specialist vehicle with a chair lift, which could accommodate equipment and the participant. This figure could not be covered by the mobility element.

Two participants we spoke to use their mobility element to visit their partners. This activity was, understandably, highly valued. In addition, one person’s partner facilitated their contact with the rest of his family. Any threat, then, to continued visits to the partner would also threaten contact with a wider group of people important to the participant. This wider group were unable to make the journey to the care home.
Holidays.

Around one quarter of the participants used their mobility element to fund transport to a holiday venue. Popular venues were in the North East and North West of England so distances were not excessive. These trips away from the care home were considered vital for the individuals interviewed. It gave them a break from other residents, it allowed them to meet up with friends who lived elsewhere in the country but with whom they had formed close and lasting friendships, and it gave them a change of scene allowing some rejuvenation to occur. Those interviewed felt that their breaks away were vital for their mental health. Trips away were costly, however, even before transport was added in. A week away could cost £800 because of the level of support needed. The mobility element was only sufficient to pay for transport and not for the holiday itself.

In cases where several people had pooled their mobility element funding into a shared vehicle, the trip away meant that the other person/people funding the vehicle were left without access to transport. Therefore, trips away had to be carefully negotiated. The level of mobility element funding meant that individuals were restricted about how far they could travel and how often they could take a holiday. Most could not afford a holiday at all, and those that could were restricted to one or two weeks a year.

Access to political representation.

Several of the people we spoke to are involved with a political or pressure group and their participation depends on access to transport paid for by the mobility element.

Four people we spoke to were members of the user group panel for Capability Scotland. Their transport to and from meetings is currently funded by Capability Scotland but one participant said they would rather pay for it themselves, giving them more autonomy on what kind of transport was used, and perhaps giving them the chance to spend time in Edinburgh after the meetings.

Another participant was a member of a National User Group Panel that campaigns for the rights of disabled people. She argued that, without the mobility element, they would have to cancel their membership, and thus her voice would not be heard.

"If I don’t participate, that is my voice lost. Nobody will hear what I have to say."
Amy.

Not only does she participate in campaigning with this group but she also feels it is her conduit to express concerns and raise problems that can then be sorted out. She felt that her attendance was "Bloody crucial".

One participant attended meetings for the Scottish Consortium for Learning Disability and regularly attended Labour Party meetings, both of which were funded by her mobility element.
Most participants had or were planning to write to their MSP about the planned cuts to the DLA. So while participants were not often physically in spaces where they had the chance to be politically active, activism was still an important element of their identity.

**Psycho-emotional impact.**

The people we spoke to were explicit about how they would feel if the cuts were made. Many used the analogy of the isolation experienced during December 2010, when snow prevented participants from leaving their homes for a three week period. The statements made by participants are emotional. The impact of the cuts cannot be determined unless the psycho-emotional consequences are fully explored and acknowledged.

"I was going up the wall. I was cranky, it was hell. Couldn’t get out for the [news]paper. Keeping in touch with the rest of the world was gone. The staff were crabby too. Felt trapped by not being able to get out."

Mark.

The impact is not just about being isolated. It is about control being removed from a group of adults that have fought to be emancipated from the legacy of care structures that have patronised and limited,

"[End of the mobility element] is taking away individuality and choice. It makes me feel small. Makes me feel very small. We should be able to make decisions about ourselves."

Robi.

And another participant,

"I want things out in the open. I want to have more awareness of what’s going on so can inform decisions. And a big part of that is having the freedom to get out into the world."

Lesley.

Professionals providing supportive care joined in with the concern over the psycho-emotional impact of the mobility element cuts.

"As a manager, if we had to try and support people who were limited on their daily choices, we would face a huge amount of frustration that could come out in challenging behaviour. Behaviour would increase, and this would give an inaccurate picture of who these people are."

Elaine.

Such concern was expressed by participants and those who work to support them in every home we visited. As another carer stated,

"Health wise, we all need fresh air and no stress. It would change the whole role of the carer in this home. We’re able now to support people’s choices and we would have to change. Freedom would come to a shuddering halt."

Andrea.
What emerged in the interviews were the voices of people who had experienced marginalisation from society but who, at some times in their life, had experienced inclusion. Amy had attended a mainstream school as her mother refused special school provision. She only moved into care structures as an adult. Fran had worked for the police force for 30 years before acquiring his impairment. Alan had completed a degree and had had a career in the media and Bill had been a librarian. They were fully aware of their isolation in the care home but saw their mobility element as a conduit to return to their homes and communities. Therefore, participants understood the consequences of the potential mobility element cuts and saw them as a direct assault on their rights as citizens to live in spaces outside of their care homes. The cuts were a threat to the right to choose to live an ordinary life.

As well as feelings of isolation, anger and helplessness, one manager described the impact on people with communication impairments and learning disabilities. For this group, there is no real possibility to explain why transport has been withdrawn. The manager predicted an increase in self-harming behaviour and behaviour that challenges. This prediction was based on behaviour shown in previous homes before individuals had been given access to outside spaces and control over activities. The manager argued that the cuts showed that the government,

“... had no acceptance of people having an entitlement to an ordinary life.”
Felix.

The cuts to the mobility element would turn the care home from a home back to an asylum, to institutionalised care hidden from communities. The people we spoke to understood the consequences of the cuts and were fearful of potential changes. The impact of removing ordinary activities from people’s lives is damaging and unjust. As Alexander said,

"How am I going to put flowers on my dad’s grave?"
Alexander.

Life after care?

This section examines the potential for participants to move to independent living. Many participants aspired to live in their own homes and were demonstrating the skills required.

Around a quarter of the residents hoped that they would, at some time, live independently in the community. These participants were taking college courses to which would help them with the skills of independent living. Transport to colleges was funded by the mobility element. Some participants have been flat hunting and two participants are keen to marry and set up home together. Apart from going to college courses, access to the wider community is vital for participants in terms of making the transition from the care environment.
Around three quarters of participants regularly do their own food shopping, sometimes as their main source of diet; others food shop to supplement the catering available in their care home. These moves towards independence are considered vital to participants. Again, transportation to supermarkets (many cannot afford to shop at retailers close to where they live but had to visit out-of-town hypermarkets) is dependent on the mobility element.

Further, the move into independent living is not a decision that individuals can make in isolation. Social work professionals in particular are required to assess and then authorise this transition. However, social workers need to be able to assess how the individual actually is, within their community. This can only happen if the person is actually accessing their community. The cuts to mobility element will prevent individuals from being able to take part in this assessment, effectively removing their chances to move to independent living.

**Access to mobility aids**

The mobility element is not only used to pay directly for transport. There are a range of mobility aids that are required before transport can be accessible. In this section, we consider examples of where mobility funding has paid for more than vehicles.

Wheelchairs have been funded using the mobility element in order to purchase chairs that more closely meet the mobility needs of the individual or that have the capacity to navigate outside terrain, compared to standard NHS chairs. Specialist wheelchairs can cost a great deal of money. One participant had to pay £5000 for theirs, and an additional £300 for the seat, and thereafter an annual maintenance fee of £80. The mobility element was their only source of funding to meet these costs.

The alternative to a specialist wheelchair was articulated by Mary,

"If I don’t have my wheelchair, I’d be in bed all the time and on painkillers because being in bed makes me sore. My life would be shit."

Mary.

Mary was clear that access to mobility not only gives her freedom but also provides a level of comfort that is necessary for her well-being. The cost to medical health services in terms of drugs and additional support care is saved because she has a wheelchair that fits her form perfectly.

In addition, several of the participants had used their mobility element to buy hoists. Although this equipment was provided in the care home, in order for participants to be able to access spaces outside of their care home, specifically spaces like college or their family home, equipment like hoists are vital. Similarly, one participant had to purchase a shower seat so that they could have full mobility and access to personal care at their parents’ home. Another participant had to buy a second chair to be able to fully navigate spaces outside of the care home.
The use of hoists further complicated access to transport. Hoists are needed to facilitate overnight stays away from the care home. Public transport could not accommodate wheelchairs plus this additional equipment. Most cars would also not be able to accommodate this equipment. Participants were forced to buy larger adapted cars which could only be afforded with the use of the mobility element. Further, the mobility element had to be saved up over a period of time in order to fund an adapted vehicle. Thereafter, the mobility element was used to pay for the upkeep of the vehicle.

**National Care Standards**

The National Care Standards exist in Scotland to set a benchmark for acceptable care in accommodation funded through social or medical care. There was a great deal of concern that these standards, that had worked well to preserve the autonomy and quality of life for people living in residential care homes, were threatened by proposed cuts. In this section, evidence will be considered that shows how a cut to the mobility element will compromise each home's capacity to meet the national care standards.

The homes we visited had been assessed by these standards and most had acquired a rating of 5 or 6 out of 6. However, the terms of the standards set requirements that could not be achieved if the DLA cuts are made.

As one manager said,

"We are a Grade 5 across the board the now. If we can’t access the community, we could slip down to a 2. There will be no access, no involvement, no participation. This is all tied in to the values of the Care Commission. This would impact on our registration and, in theory, if we get a 2 we could be closed down."

Louise.

**Alternative sources of transport funding.**

To fully evaluate the consequences of the proposed cuts, we tried to establish whether monies could be diverted from other sources in order to meet the costs of transport.

We were told that there are no alternatives. We heard multiple cases of families subsidising the mobility element in order to facilitate trips home. Most participants could not call on family for money because families did not have this resource.

Private care homes had limited monies available to care. For example, one home had a bus that was effectively shared by 300 residents over three care homes. This same home had to resort to bringing in donated clothes for residents because their care packages had been cut so substantially.

A care home run by Capability Scotland is funded through the local authority and has seen a decrease in funding of care packages of between 8-10%, with more decreases threatened. Another home has been told that the budget could be cut by 20%. So, there is no scope for these organisations to provide transport.
Conclusion.

Care home residents use the mobility element of their DLA to help fund a wide range of activities and, if this payment is removed, their opportunities for participation in the mainstream will be greatly reduced. Without access to this money, many residents will no longer be able to leave their homes, get out and about, go shopping, visit their family or have their family visit them, go to clubs and participate in local organisations or take part in leisure activities enjoyed by their peers. This money is very important in helping promote independence and autonomy and in ensuring that care home residents are able to exercise choice in their lives. There is a real danger that, if it is withdrawn, we will see a return to the days when care home residents did not leave their homes and spent all their lives living within the confines of their institution. Many of the older residents we talked to could remember those days and were genuinely scared at the possibility that they may have to live under such conditions again.

One of the great strengths of the DLA as it is currently formulated is that it allows disabled people choice in how the money is spent and it plays a crucial role in helping people stay independent or achieve independence. Many people living in care homes value this and want to live as independently as they can for as long as possible. Some residents also saw a future beyond the home and were planning for a life outside of the residential care home setting. This desire was in part stimulated by taking part in activities outside of the home and, through this, realizing that living independently in their own homes was a possibility. Without the financial support afforded by the mobility element of the DLA, this is unlikely to happen.

Further, not only will this change impact on care resident’s ability to access health and social care services and affect the quality of care and support they receive, it will also affect those services themselves. For example, unless alternative funding streams are introduced, more stress will be placed on the patient transport service and the role of general practitioners in delivering care to residents will have to be re-examined.

Given this, it is not surprising that the initial proposal to remove the mobility element of the DLA from residents in registered care was met with such hostility by the large number of organisations who work with disabled people and from care home residents themselves, as the recently published response to the public consultation on reforms to DLA testifies\(^\text{13}\). An outcome of this consultation has been a commitment to review the plans to withdraw this funding:

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“The Government has listened to the strong concerns raised by individuals and organisations about the Spending Review proposal to withdraw the DLA mobility component from people in residential care. The Government will not now introduce this measure as planned in October 2012. We are both reviewing existing and gathering further evidence to inform how best to proceed. Meeting the mobility needs of people in residential care will now be considered as part of the wider reform of DLA. The Government is committed to ensuring that residents of care homes are able to get out and about, and is therefore looking to remove overlaps in funding, not mobility.”

Our hope is that this report can be fed into this review and that the data collected can help the UK Government as it develops its plans to reform the DLA. At the outset of this review process, Maria Miller, Parliamentary Under Secretary of State and Minister for Disabled People, in the ministerial forward to the public consultation document that opened the review stated:

“We are steadfast in our support for the principles of DLA, as a non-means-tested cash benefit contributing to the extra costs incurred by disabled people. However, we need to ensure that the benefit reflects the needs of disabled people today, rather than in the 1990s.”

The data collected as part of this review will provide the Under Secretary of State with the information she requires to ensure that the review fully meets the needs of care home residents and that future plans do not see the introduction of an inferior, unreasonable and unfair system and that they retain the mobility component in the new PIP for people in residential care homes.

It is also our hope that the Scottish Government will be able to take heed of the evidence gathered about the extensive use of the mobility component of DLA by people in care homes and that they are able to exert pressure on their Westminster counterparts to ensure that residents of care homes are not disadvantaged by any future changes in the support they receive.

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14 Ibid P.6