Holes in the safety net:
The impact on disabled people of the abolition of the severe disability premium within Universal Credit
Report 2

Contents of the report

Summary

From October 2013 the government will begin the process of transforming the welfare system, combining a number of different key benefits into 'Universal Credit'. This process will mean big changes in the structure of financial support for lower income families both in and out of work. Under the new system, financial support for some groups of disabled people will be much lower than current support available for people in the same circumstances. There are three main groups who are likely to receive considerably less financial support under Universal Credit:

- Most parents of disabled children
- Severely disabled[1] adults who live on their own or with dependent children and do not have a carer[2]
- Some disabled adults who work.

The government have stated that any money saved by these cuts will be used to raise the amount that all severely disabled adults receive. This means that severely disabled adults who live on their own will receive considerably less than they do now even when savings are made as the addition they receive to cover the extra costs of living on their own will be redistributed between all severely disabled adults – including those who do not face these additional costs.

This report looks at the likely impact of these changes on severely disabled adults who live on their own (or with a partner who is also disabled or just with dependent children) and don't have a carer. All severely disabled adults face extra costs. However those who live on their own also have additional costs not faced by those with a partner. In the current system this group are eligible for the Severe Disability Premium (SDP), currently worth about £58 a week, but under Universal Credit there will be no additional help with the extra costs that this group face as a result of having no-one to assist them.

The government says it is abolishing the SDP with the introduction of Universal Credit in order to redistribute the money to disabled adults with the greatest needs. The money saved from these cuts will be redistributed to all those in the 'support group' of Employment Support Allowance (ESA) including those who do not face the additional costs of being disabled and living alone.[3] This will mean a loss of £58 a week (over £3000 per year) for 'severely disabled' people with no adult to assist them, who are not in the ESA 'support group'. Even those severely disabled people in the 'support group' will lose, as the extra money received will not make up for the lost £58. It is likely to mean that this group, who face the highest costs and are the most disadvantaged, will be £28 a week worse off.

Around 230,000 people on income support or jobseeker's allowance (JSA) receive the SDP. The DWP reports that 25,000 lone parents are currently in receipt of the SDP. Additionally there will be people on employment and support allowance (ESA) in receipt of the premium but the numbers of these are not centrally collated.

The government has offered no evidence that severely disabled people who live on their own do not need this addition or that they do not face extra costs. The inquiry set out to collect evidence from disabled people about the extent to which this support is needed and the likely impact of withdrawing it. A survey conducted by the inquiry on this issue collected detailed evidence from 1243 disabled people.

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1 We use the term 'severely disabled ' adults to refer to the benefit system definition. In the current system a 'severely disabled' adult is someone who receives the mid rate or the high rate of the care component of Disability Living Allowance (DLA). If someone who is severely disabled lives with a partner who is also severely disabled they will also lose out financially under UC.

2 When we reference 'don't have a carer' in this report, we mean someone who does not have anyone being paid carers' allowance to assist them.

3 See appendix for further explanation of the 'support group' of Employment Support Allowance (ESA)

Findings

The survey and a parliamentary event provided very clear evidence that disabled people who live on their own, and do not have a carer, faced considerable additional costs as a result.

- Some extra costs were very clear especially where it came to household chores and minor household repairs. There was repeated evidence that people had long lists of things they could not do and had to pay for (or leave undone) that a non-disabled person could easily manage. Other costs, such as transport, were less clear cut than those listed above but were frequently mentioned and it appeared that in many cases costs would be much higher for disabled people living on their own.

- The majority of respondents who would be eligible for the SDP were receiving no outside help from social care or any other agencies and were only slightly more likely than those living with a partner or who had a carer to be receiving any help. Even in the small minority of cases where social care was in place it was usually just for basic care essentials such as help getting out of bed, washed and dressed. Help with cleaning and other household chores usually had to be paid for privately.

- Some were in very difficult circumstances and clearly were really struggling to function on their current level of income. This group are clearly at greatest risk of social exclusion yet many were unable to afford to go out other than for essential trips. They were clearly very distressed at the idea that people in similar circumstances would be expected to manage on an even lower level of income than they currently received.

- Some respondents reported that their relatives lived at a distance and so could not be there often enough to claim carers allowance. Instead of relying on the help from one carer, caring enough hours to receive carers allowance, they were being supported by a network of relatives and neighbours. They stressed that these networks were dependent on them being able to pay the expenses of those travelling distances to assist them and being able to buy small gifts for neighbours. For them, the SDP was vital for this purpose.

- The government has argued that disabled lone parent households do not need the SDP as the household should be supported by social care so the children should not be doing the caring. However it was clear that children were having to take on considerable caring and household responsibilities particularly if one of the children was over 10 years of age. Only 27% of households with a child over 10 was receiving any extra help at all from social care or any other agency. The outcome of reducing the income of these households can only be that the children have to take on even more caring responsibilities as money will not be available to pay for any extra outside help.

Conclusions and recommendations

Severely disabled adults whether living alone or with carers, face very challenging circumstances and face costs not faced by non disabled adults. However, our evidence clearly demonstrates that those who live on their own have additional costs which are not faced by other severely disabled adults. The SDP currently only goes partway to meeting these costs. The evidence from the inquiry clearly demonstrated that the SDP or some equivalent addition to specifically cover these additional costs is absolutely essential. **Any money to raise the level of income of all severely disabled people must be new money and not raised by taking this essential addition from those severely disabled people who face the greatest costs.**

We recommend that the Severe Disability Premium be retained. We are mindful that the government want to limit the use of additions within Universal Credit. For carers, there will quite rightly be a carers' addition. If it is not felt possible to maintain a severe disability premium, then we recommend the introduction of a self-care addition paid at the same rate as the carers' addition to anyone who does not have someone caring for them and claiming the carers allowance or the carers premium.

Introduction

Reform of the welfare benefit system was a key priority for the government on coming into power. Numerous incremental changes made to the system by successive governments have resulted in a complex system with high levels of error and millions of people failing to claim their entitlement.

As a result, the 2012 Welfare Reform Act has legislated for the biggest change in the welfare benefits system since its conception over 60 years ago. The centre piece of the Act is the introduction of the Universal Credit which will replace much of the benefits and tax credits system for people whether in or out of work.

The government intends to simplify the system, make work pay and protect the most disadvantaged disabled people. Baroness Grey-Thompson's inquiry, supported by Citizens Advice, The Children's Society and Disability Rights UK, was established to examine whether Universal Credit is likely to achieve the government's aims for disabled people and their families.

Whilst many people may be better off under Universal Credit, this inquiry identified that several key groups would lose financially under the new system. These groups are:

- 100,000 families with disabled children stand to lose up to £28 a week[1].
- 230,000 severely disabled people who do not have another adult to assist them[2] will receive between £28 and £58 a week less than currently.
- Around 116,000 disabled people who work will be at risk of losing around £40 per week[3].

This means that around 450,000 disabled people could stand to lose out under Universal Credit once it has been fully implemented. Current benefit claimants who move onto Universal Credit will not see their benefit cut immediately, however they will have their level of benefit frozen with no increases to take account of rising prices. In addition they may see their support cut immediately if their household circumstances change. This report looks at the likely impact of these changes on 'severely disabled'[4] adults who live on their own (or with a partner who is also disabled or just with dependent children) and do not have a carer. At present, 'severely disabled' adults who live alone, without a carer,[5] are eligible to receive the SDP as part of any means tested benefit they receive. As well as the costs which all severely disabled people face and which are covered by Disability Living Allowance, those severely disabled people who live alone and without a carer face additional costs as a result of living alone and not having someone paid carers allowance to assist them.

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1 See Chris Grayling 08/06/2011, in response to parliamentary question: http://www.theyworkforyou.com/wrans/?id=2011-06-08a.57941.h&s=curran+section%3Awrans+section%3Awms#g57941.q0

2 For full definition of this group see Appendix 1. Number of recipients based on those receiving the SDP within their Income Support or Job Seekers Allowance entitlement - see, http://www.theyworkforyou.com/wrans/?id=2011-06-10c.57981.h&s=severe+disability+premium+section%3Awrans+section%3Awms#g57981.q0 this is likely to be an under-estimate of those affected, since the full number will include households receiving the SDP as part of their Employment and Support Allowance entitlement.

3 the current system many disabled people are entitled to extra support to cover the costs of working. The 117,000 figure is based on those households currently receiving the 'disability element of Working Tax Credit' (See http://www.hmrc.gov.uk/stats/personal-tax-credits/cwtc-main-apr12.pdf table 5.1) who would be at risk of losing in work support under Universal Credit. Those who would qualify for the WRAG or support group (see appendix) will not lose out.

4 use the term 'severely disabled ' adults to refer to the benefit system definition. In the current system a 'severely disabled' adult is someone who receives the mid rate or the high rate of the care component of Disability Living Allowance (DLA).

5 We use the phrase someone who 'doesn't have a carer' to mean someone who doesn't have someone paid the carers allowance benefit to assist them. People may be paying privately for a carer but this is coming out of their own money or they may be getting some help with personal care from social services but are likely to have to contribute to this and will still have extra costs

Background to the change

It has long been recognised that disabled people face many extra costs to enable them to live independently. There are three main sources of support for these additional costs:

Non means tested system:

Disability living allowance (DLA) is a non means tested benefit. It is shortly to be replaced by a personal independence payment (PIP). In both DLA and PIP there are two components – a care component and a mobility component. DLA and PIP cover the extra costs all disabled people face as a result of their extra disability-related expenditure. However both DLA and PIP use the level of functioning as a proxy measure for extra costs. Absolutely no account is taken of whether, on the one hand, the person has a carer or partner who can assist them or, on the other hand, has no-one to assist them and is going to have to pay for someone to help them with that task. There are, of course, many costs which severely disabled people face regardless of whether they have a partner or not. For example, someone who is unable to walk or use a manual wheelchair is likely to need a powered wheelchair to get around regardless of whether or not they have a partner.

Means tested system:

The components (WRAG and support) within Universal Credit, and the disability premiums within the current system, recognise that those who are on a very low income, and are likely to be on that low income for the long term, need extra support. It is a recognition that if someone is likely to be unable to work, as a result of a health condition or disability, or is at a disadvantage in the workplace, either permanently or for a long period, then they are more likely to struggle to manage than someone who is out of the workplace for a short period.

The severe disability premium within the current system specifically recognises that, in addition to the extra costs that all disabled people face and that are covered by DLA / PIP and the above components and premiums, there are also extra costs that are faced by disabled people who live on their own when no one is paid carers allowance to care for them.

Social care:

Local authorities have the responsibility for drawing up a social care plan for a disabled person who requests support. It is difficult to be clear about the amount of support someone will receive because the amount of help varies between different local authorities and between different individuals. If someone does access social care then additional payments but not basic living costs payments are taken into account when deciding on the contribution the person has to make towards their social care. They will disregard any money which is required for disability related costs but this often does not cover many of the more indirect additional disability related costs such as maintenance of their home. The inquiry therefore needed to collect evidence about the extent to which severely disabled people are receiving social care, what that social care was covering, the extent to which their contribution for the social care they received was eating into the support for other areas and if there are additional needs which are not covered.

The severe disability premium

In order to qualify for the SDP a claimant must:

- Be 'severely disabled' - receipt of the middle rate or higher rate of the care component of DLA is used as a proxy to indicate that someone is severely disabled and has very frequent care needs.

- Be treated as living on their own – they can be treated in the same way as someone who lives alone for the purpose of the SDP if there is no other adult in the household or they live with a partner who is also disabled.

- Be on a low level of income - It is only payable as part of a means tested benefit.

The government is abolishing the SDP with the introduction of Universal Credit (UC). Support for disabled people under UC will be based on the assessment process for employment and support allowance (ESA). Those with the most severe level of functional impairment as in the current benefit system will be eligible for the 'support' component. The government is planning to use any savings to increase the level of the support component but even when they reach their target, people receiving the support component but living on their own will be £28 (about £1500 a year) worse off than people in that position are under the current system. These are the group of people who are likely to face the highest costs yet they will be worse off under UC.

Those who are 'severely disabled' but without sufficient functional impairment to be placed in the 'support' group but who live alone or with a 'severely disabled' partner and have with no one to assist them, or are assisted by dependent children, will be about £58 per week (over £3000 per year) worse off.

Around 230,000 people on income support or jobseeker's allowance (JSA) receive the SDP (with the numbers on employment and support allowance (ESA) in receipt of the premium not centrally collated.) The DWP also reports that 25,000 lone parents are currently in receipt of the SDP.

Prior to the introduction of the SDP with Income Support in 1988, supplementary benefit had an addition called a 'domestic help allowance' which was payable to a severely disabled adult who lived on their own – it was also payable if they had children under 16 in their household or a partner who was also disabled. It was payable even if they had a home help from the local authority if that did not provide sufficient help for their needs. When Income Support came in, the various extra allowances were simplified but the government recognised the ongoing need for severely disabled people on a low income and who lived on their own to receive extra financial support. The SDP was therefore introduced.

Given that it has been recognised for so many years that severely disabled people who live on their own are likely to have extra costs which those who have able bodied partners or carers are unlikely to face, we are very concerned that this efficiently targeted support is to be withdrawn without the government producing any evidence that the needs are no longer there or that the necessary support is now being given by another agency.

Our report Disability and Universal Credit highlighted the financial implications of the restructuring of UC for different groups of disabled people. It revealed a number of anomalies in which groups will lose and which will gain. The additional support in the

SDP given to severely disabled single people living on their own or just with children (often acting as carers) to help cover the extra costs they face as a result of living alone is being redistributed to all in the support group including those who do not face these extra costs. The current government has produced no evidence that this redistribution of support will better target those who most need the support, nor that the current level of extra financial support for those with a severe level of impairment who live alone without a carer is unnecessary.

Government rationale for the abolition of the SDP

The government has put forward three arguments as to why the SDP should be abolished:

- It will simplify the system
- DLA/PIP covers the extra costs disabled people face
- Social care provided by local authorities provides carers for those who do not have a carer.

The government has argued that any money saved by the restructuring of support will go to those in the greatest need, by (eventually) raising the amount for everyone one in the support group.

Some key questions arise from the abolition of the SDP and the government's stated rationale.

The key questions:

- **Is there evidence that the £58 currently paid to those who do not have a partner or carer is unnecessary?**
- **Does the evidence demonstrate that the restructuring which the government proposes will achieve its aim of supporting those with the greatest needs?**
- **Does the evidence demonstrate that those who live on their own face extra costs compared to someone, with a partner or someone paid carers allowance to care for them?**
- **Are any extra needs being met by outside agencies?**
- **What evidence is there of the likely impact on people's lives of the abolition of the SDP?**
- **Is there a way in which extra support can be given to disabled people living on their own whilst not making UC more complex?**

To answer these questions evidence is needed about the extra costs faced by disabled people who live on their own, which those who have a carer do not face, and the extent to which these extra costs are being covered by extra support from outside agencies. Evidence is also needed about the likely impact on new claimants of a reduction in the level of benefits.

Methodology

This report examines the evidence we received from the 1284 disabled people who completed the detailed online survey. It has provided some useful statistical information and a great deal of detailed qualitative information about the extra costs faced by disabled people who do not live in the same household as a non disabled adult. Of the 1243 disabled adults who completed the survey, 885 lived on their own or with another disabled adult or with dependent children. 406 disabled people out of this group also identified themselves as receiving a level of DLA which would qualify them for the SDP. All of the textual analysis of extra costs was done on the responses of this group.

However, it was useful to have the responses of the other respondents as this gave a larger base to look at other groupings such as by type of impairment and to compare the group of people who could not be treated as living on their own with those who could when looking at the help received from outside agencies.

The respondents were individuals living in different circumstances with differing types of impairments or health conditions, living under different local authorities and varying in the care received from the local authority or other agency. Some had family or friends providing a network of care whilst others were living very isolated lives. However, the large numbers of people who completed the survey and gave a wealth of detail about their lives, the barriers they face, the support they need to overcome those barriers and the support that they actually receive allows some important general conclusions to be drawn.

The extra costs

All the respondents quoted lived either on their own or with another disabled adult or lived just with their children and no-one was paid carers allowance for looking after them. They also all received either the middle rate or the high rate of the care component of disability living allowance (DLA).[1] They would, therefore, all be eligible for the SDP to be added to any means tested benefit they would be entitled to. The questions about extra costs were split into five main sections: Transport, Personal care, Social activities, Household tasks and Other. For each section, people were asked to estimate how much extra cost they incurred because they did not have someone who was paid Carers Allowance to assist them and also did not have a non disabled adult living in their household. They were also asked for a description of any extra costs they faced. It was clearly difficult for people to separate out the extra costs which were a direct result of living alone and not having a carer whereas it was much clearer in the detailed open responses so we used textual analysis to look for the main themes in each section.

Help with costs from outside agencies

The respondents were also asked about the support and help they received from other agencies, such social services or charities. This enabled analysis of the support available at different levels of DLA for different groups and the extent to which outside help could cover any loss in means tested benefits.

Impact

At the end of the survey, respondents were asked what the likely impact on their lives would be if they had to manage on less than they currently receive. It was made clear that they would be covered by transitional protection if their circumstances remained unchanged but that their answers would provide some evidence on the likely impact of UC on the lives of new applicants.

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1 See appendix for an explanation of the different rates of DLA

Survey results

This section analyses the evidence produced by the survey and draws conclusions based upon it.

Transport costs

The people responding to this survey had a wide variety of health conditions and impairments – they were in very varying circumstances and faced very different barriers. Some key themes, however, emerged. More than half of the respondents specifically mentioned the need for taxis. Just under half mentioned the use of motability to pay for a car or van and many also mentioned the use of powered chairs. Very many mentioned a combination of costs e.g. the use and costs of a powered chair plus having to use taxis for longer distances or the importance of a car through the motability scheme but the need to also use taxis when not able, because of their condition, to drive.

There is clearly no distinct dividing line between the extra costs due to living on your own and the extra costs which would also be faced by someone with a carer. Some of the costs mentioned below would probably be faced to a greater or lesser extent by those with a partner or carer. It will depend on many factors and will vary from household to household. Someone with a partner will still wish to be independently mobile. However it was clear there were costs which clearly would be unlikely to be faced by someone who had a carer such as having to pay someone to drive their vehicle when they are unable to drive or having to pay for a taxi for every trip out of the house.

For some, taxis were the only means of getting out of the house but, as a result many were clearly limiting the number of times they went out each week. GP and hospital appointments were frequently mentioned as was shopping.

Some gave specific examples of the cost:

Transport most definitely, an appointment to the doctor or dentist costs me £12.00 which is the minimum taxi fare.

I had to accept the flat I live in now as the Council said it 'met my needs' and if I didn't accept it I would have to 'bid' on properties like everyone else. This flat is at the other side of the city so to visit my daughter or my friend(s) cost me £20 in taxis respectively.

A number of people pointed out that they needed wheelchair accessible taxis and that this made the cost even greater:

Taxis are way beyond my means (£50 return trip in a powered wheelchair adapted taxi is average).

The cost of the powered chair was in addition to the cost of taxis or adapted vans:

Need to run an adapted van that will take my wheelchair, £650pa. Need to repair and, recently, renew my wheelchair. £3500.

Insuring and repairing specialist powerchair £280 a month

Many did own their own car through the motability scheme but pointed out that they still faced a lot of extra costs. For those living on their own there were often occasions when they were forced to use taxis because they were unable to use their car. All their DLA high rate mobility was used up paying for their car so the cost of taxis was extra. They would face some of these extra costs whether or not they had a partner or carer. However there are other costs which someone who had a partner probably would not face such as having to pay someone to drive the car or very simple maintenance costs or having to rely on taxis when unable to drive or needing someone with them whenever they go out and so having to pay their costs.

When I can't drive I have to pay others to drive me as I depend on my van to carry my mobility scooter around. I pay to have my van taken to have the tyre pressure checked, the windscreen washer fluid replaced etc, i.e. all the regular maintenance which would normally only take an active person a minute or two.

Need someone to drive me £13.50 an hour

Need to pay someone to drive me anything longer than a couple of miles or get a taxi. I am unable to use public transport.

When I am too ill to drive I take taxis and therefore also need to pay for these whereas if I lived with a non-disabled partner that person could conceivably drive me.

Social activities

Survey respondents were asked about the extra costs of social activities. 44% of people making a comment in the open response box said that they saw someone socially once a week or less and 40% of people said they had no or virtually no social life at all. For most it was the high cost which prevented them from taking part in social activities outside of their home, and they had to prioritise other costs. This comment or similar was a very common response:

I cannot afford social activities

Many people pointed out that going out was so expensive because they had to pay for the time of a carer and also all their expenses as well as the extra expense of transport as covered in the previous section:

I don't have any social activities - it is just too expensive after paying for a carer to go anywhere with me that is essential. Social activities are not affordable. If I was to have a social life it would cost for 4 hours £30 for an attendant, plus petrol, plus ordinary costs.

...as I need someone to feed me and hold up a drink I have to pay for someone else in a cafe or pub or restaurant.

The inability to afford to go out socially will have a number of implications. One of the witnesses at the evidence session who has a severe sight impairment and lives on her own pointed out that, in the period after she was made redundant from her previous job, she would have been unable to stay active in the community without the extra money from the SDP, which enabled her to take part in activities (which would have been impossible without the use of taxis) which in turn helped her to maintain her self-confidence and subsequently led to her being employed in her current job.

Some people pointed out that cuts in services meant that social activities they had previously relied on were no longer available:

I used to be able to go out 3 times a week to a support group -that has faltered ..... when I had a support group to rely on I felt I had a safety net

My only social activities each week is a day centre. I have to pay towards the cost of this plus paying for transport that Cumbria social services have just decided to start charging people for transport.... from July 1st. As I live about 10 miles from the day centre ...I'm now having to re-consider going to this group as the costs are so ridiculous.[1] I've been to this group for 9 years & have built up friendships there - my only social contact. But we're all working age adults and none of us can get jobs due to our disabilities. This might well be the death of the day centre altogether. Then my life will most likely be of poorer quality than someone banged up in prison.

What social activities? .....Social Services no longer provide a social element in their support package to enable me to take part in activities.

For many the key social event was the shopping

I cannot partake in social activities, visiting the supermarket is as social as I get.

But some because of the high cost of taxis could not afford to go out to do their shopping and saved money by shopping online and having the shopping delivered:

..... I have to get taxis. I rarely go out as I don't have a lot of money left after putting aside money for bills etc. I even have to do my shopping online and pay extra for delivery.

There were a few activities mentioned by one or two people which were clearly prioritised by that individual such as swimming or art and several mentioned going out just for special occasions such as birthdays. Some people mentioned travelling to meet friends or relatives as a key cost:

1 Cumbria Social Services confirmed that they have just introduced a fee of £1.50/mile which would amount to £30 for this respondent plus the cost of the daycentre itself. The fees are means tested but when talking into account benefits but usually only directly disability related expenditure is allowed to be excluded from the income taken into account.

Use of my motorised wheelchair to get to friends or, if too far away for my batteries to sustain a return journey a £50 return taxi job.

The one social activity which was mentioned by a significant number of respondents was the internet and communication over the internet. This has clearly become an important lifeline for many people. It must be borne in mind however that this survey was conducted online so clearly excluded those with no internet access. The social exclusion of that group is likely to be even greater.

Mostly, though, I don't have a social life except online, so I suppose that's the real cost.

Unexpected expenses that may arise i.e. fixing or replacement of say a computer.... without which I would not be filling in this form, keeping in touch with the outside world, shopping & generally achieving some sense of belonging in the world!

Clearly those living on their own are more likely to be socially excluded than those living with a partner so any further reduction in social activity must be a cause for concern.

Household tasks

This was an area where people clearly found it much easier to assess what extra costs they faced as a disabled person living on their own. As one person pointed out 'so trivial a task as to be unnoticeable for a healthy person' such as 'receiving a package' can become a major task for him:

It involves: *collecting post from the shed (postie leaves it if parcels as I cannot get to the door) to opening parcels, recycling the packaging, putting it out in the wheelie, putting the wheelie itself out.*

The list of jobs which respondents needed help with but which they thought an able bodied person would have done very quickly was very similar and occurred time and again – most people mentioned cooking, cleaning, small decorating and maintenance jobs. Lists like the one below were common:

decorating, gardening, cleaning, cooking, washing, any dIY, hoovering, changing my sheets buying pre prepared products for when I do not have a carer.

People were mainly managing by a mixture of one or more of the following ways: paying for some assistance, receiving some help from friends or family or leaving some jobs undone. Not everyone has family or friends to rely on:

I don't have family who can do these things for me, and have lost touch with most of my friends – people are willing to help for a while or for odd things, but it becomes a one-sided relationship and you feel like a burden,

.....I need to pay for every job that needs doing both inside and outside of my home.

Every possible job that an able bodied person can do! The problem is that jobs get left undone as I cannot afford to pay someone to do them.

It was clear that having their home cleaned was a priority for most and many people were paying for a cleaner even if some of the other repairs were being left undone:

I must have paid domestic help as many usual domestic jobs are beyond me, such as floor cleaning, bed changing, using washing machine, all reaching up tasks. With no relatives or friends nearby I would live a life of rot and decay

……. I pay for a cleaner £30 per week - money I don't have. My outgoings are now a lot more than my income so I'll soon be in debt. Costs are rising daily but my income has only risen by £2.05 since April last year.

Needing help with cooking was another area mentioned by most respondents. The most common way of managing this was the use of pre-prepared food but many were concerned about the resulting unhealthiness of their diet:

…..Takeaways are very expensive and not healthy at all.

…..Need to buy all prepared food - have ended up living on bread and cereal because I cannot access nutritional prepared food

…….I buy the ready meals from Wiltshire farm foods but they are far from cheap. I can only have one meal a day for myself because I don't need much to eat because of my sedentary lifestyle ……..

I need help to prepare the food and ready meals are creating problems…..my health is suffering ballooning weight on carb rich diet

Others were prioritising a healthy diet but this meant juggling other things:

I have diabetes and heart disease. I have to eat a strict healthy diet. This is fine in the summer, although with the rising cost of food it is stretching the budget and I am having to cut back in other areas, i.e. I have no life outside this house. I will NOT be able to maintain this diet in the winter and keep warm.

The maintenance of their home (and for some their garden) was clearly something that worried people a great deal. Several mentioned that it was a condition of their lease or tenancy that they kept it well maintained.

…….my lease requires that I redecorate every 7 years (can't afford it), my garden is an overgrown mess (can't afford it), many small DIY jobs are simply not done (can't afford it).

£10 per week to get garden mowed part of my tenancy……

The regular jobs such as putting out the rubbish and small essentials such as changing light bulbs had to be paid for unless they had a family member or friend who could help them:

fixing toilet, fixing shower socket, decorating, changing light bulbs, cleaning the back yard…….. fixing things that get broken, unblocking the outside drain gulley, re-grouting the bath, removing the curtains to put them through the washer. Cleaning and hoovering the car, washing the windows, I could go on for ever

Need to pay for help with even things as simple as putting the wheelie out. I have to pay someone to do anything that needs doing that a partner could do if I had one

Several people reflected on the difference between what they are able to do now and what they would have tackled before they were disabled or when they had a partner who was not disabled:

Cannot do DIY now husband has died… so have to pay for everything…husband did all this

All household repairs, even the smallest job……. Before I was disabled, I only paid for the largest or most specialist work.

Many reflected on the jobs that need doing but they are unable to afford:

……I have been here over twenty five years and it needs redecorating as it is now very shabby,

……..No windows now open but I can't afford to get them repaired…..

I do not think the Government has any idea what it is like to be on disability benefits long term. There is no more slack to be cut. There is nowhere to go when the washer breaks down, when you need help in the garden, I cannot leave the heating off any longer. I am doing without the maintenance contract on my stair-lift because I haven't got £250 but I live in fear of it breaking down and me being back to crawling up and down stairs on my bottom. Please realise that we have paid into the benefits system when we were well and working. ……

Personal care

Within this area we have included the very basic essential costs of functioning such as getting in and out of bed, getting washed and dressed and getting to the toilet. Unsurprisingly therefore this was the one area of extra costs where a significant minority were receiving help from social services or other agencies. They usually had to make a contribution to the cost from their benefits. A number mentioned choosing to pay for a carer privately because then they could control expenditure more effectively. There were however extra costs over and above the cost of a carer or their contribution to the care package.

The majority of the respondents mentioned the very high cost of specialist aids and adaptations, some had been helped with some of the costs but others had had to buy them themselves. There was in addition the maintenance of existing aids, the extra costs of laundry and replacement of clothing bedding etc. Some of these are costs which would also be faced by someone who had a partner but perhaps not to the same degree.

It was obviously difficult for people to separate out with these sorts of costs which costs they would incur even if they had a partner or carer but it was clear that there were costs which they would be less likely to face if they did not live on their own especially if they had no support from social services as was true in a majority of the cases.

I have to pay someone to read my post and help me deal with it … I have to pay someone to go to the local walking group called Action for Health so I can take part (and any other social events), I have to pay someone to take me to medical and dental appointments, ……I had to pay for a braille dosette box/talking scales/talking jug etc as none of these are considered essential if you live alone, I have to pay someone to go with me to get cash from the building society …, I have to pay for recipes to be recorded, I have to pay for CDs to be labelled, I have to pay for a braille labeller, dictaphone and penfriend device for different information use, I have to pay for a colour detector to try to match clothing, I have to pay for ironing as I kept burning my hands, ……..

Some people did receive help from a relative who was not a paid carer but had to pay for their travel expenses:

…..my daughter takes me to hospital, dentist, drs, shopping or if I want to visit friends. I put around £50/60 in petrol as daughter lives 30 miles from me and also comes to help with showers etc

Many of the respondents however are paying privately for personal care:

All ongoing costs, paying for carer to get me out of bed, help me shower, dry me, dress me, cook meals, serve meals, help me change clothes when become soiled, undress, put me to bed. I pay for an alarm system with fall detectors etc.

…… pay an independent carer privately to assist with bathing/ personal hygiene

However it was clear that for many this was about essential functioning. Several mentioned the even higher costs of employing a carer for help with social activities because in addition to the hourly rate they would have to pay for the carer to take part in the social activity, their fares, snacks etc.

I pay for carers to help me function at a basic level

Many mentioned the extra cost of specialist equipment:

Stannah stairlift was over £3,000; insurance and maintenance contract is now on-going and costs £270 per year; Nebulizers - battery-operated portable and a heavy duty electrical one (each costing over £200), serviced yearly and have to have new parts. - so much extra equipment I have bought in the past … - the costs run in to tens of thousands of pounds.

In some cases they received outside help, in other cases relatives were helping out with the costs:

I have purchased many disability aids to combat limited movement as well as using aids and adaptations provided by social services and community care grants

My sister .....has also helped me to get a hard wearing durable reinforced bed, extra support rails, and an oven which switches its self off and alarms when ready. Sometimes my sister buys me little reminder gadget things that actually help like my phone which she set to remind me to do things.

If we had only included those on means tested benefits then many of these extra costs would have been artificially excluded because they were already unaffordable. In this section in particular, there are also differences because of the different levels of care offered by different local authorities and what aids and adaptations are paid for by them. Several people mentioned that they had been refused help or had help withdrawn:

.....so to have any hope of ever leaving the house I have to have a powerchair. I live in a hilly place and have specialist seating and size needs so have specialist build powerchair £280 per month (£450 upfront had to come off credit card). ..... OT managed to get funding for wheelchair ramp which took a further 8 months to materialise....on the understanding I fund my own chair....

The OT can only provide the most basic of specialist equipment so I've had to buy the equipment that makes daily living easier to manage

My care package has been cut by 6 hours per week so I'm now having to meet some of my personal care costs myself.

Some were receiving help with personal care from the LA but the contribution they had to make meant there was less money for other essentials – money that is available to those with a carer receiving carers allowance

Personal assistants (largely funded by the council but I pay much of my DLA care payment towards this cost)...

A number pointed out that they were already unable to pay for the essential care they needed:

I am unable to keep myself clean, or in clean clothing and bed sheets as I cannot manage it and I cannot afford the amount of care I need under the current system, never mind without (the SDP)

Need help bathing cant afford it so rarely manage to.

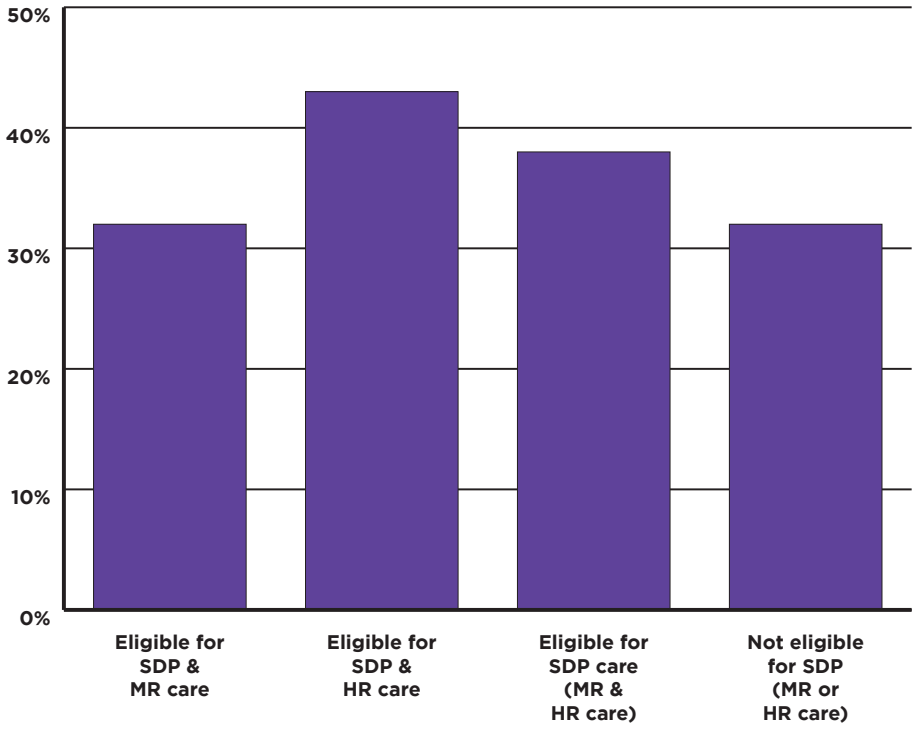
I have my bed changed my pads changed about twice a day because I cannot afford to have my carer help me more often so I stay wet and with faeces for very long period , I have open wounds as a consequence

..... I need special taps, special shower, stair lift and a ramp to my front door in order to live independently but cannot afford them.

Support from an outside agency

We asked all respondents if they received any help from any outside agency or support such as from their local authority social services or from a charity or other agency. **Even amongst those living on their own and receiving the highest rate of the care component of DLA less than half (43%) were receiving any outside help.**

Figure 1: Percentage of all respondents receiving outside help



As can be seen from the chart[1] support from outside agencies was more likely in the case of people on the high rate of the care component (HR care) than those on the middle rate (MR care) but even in the case of high rate of the care component less than half (43%) received any help at all.

37% of those eligible for SDP were receiving any outside help. However of the 181 respondents who received the mid or high rate of the care component of DLA but who didn't live alone (and couldn't be treated as someone living alone for the purpose of the SDP) only a slightly lower proportion (33%) were receiving support from an outside agency.

The evidence implies that living on your own without a carer only gives a disabled person a slightly increased chance of receiving help from an outside agency. The type of impairment had a much greater influence on whether people received help from an outside agency than whether they lived on their own. For example 51% of the whole sample of those who said they had a learning disability (this included people who were not living on their own and people who were only receiving the low rate of DLA care) were receiving some support from outside agencies, whereas only 28% of the whole sample of those who said they had a physical disability were receiving some support from outside agencies.

Physio every 2 weeks, Consultant yearly, occupational therapy 6 months, PMC 6 months

1 See table in appendix for percentages

When we categorised responses into levels of care **we found only about 14% of people living on their own and receiving high rate or mid rate of the care component of DLA received two hours a week or more of help. About 8% were receiving 10 hours of care or more of care from an outside agency.** However even where there was 10 hours or more of care a week - they were having to pay part of their DLA towards their social care, often having to pay for additional care and help with cleaning etc and facing extra costs that someone with an able bodied partner wouldn't face. For example the following respondent is in receipt of higher rate of the mobility and middle rate of the care component of DLA. The following includes just some of the extra costs mentioned by them:

I get ten hours care a weeks I have to give the council a big chunk of my DLA care…… because I don't have a full time carer plus I have pay for other services as I don't have all social care hours I need….. If I'm having a bad day or need extra things doing I have pay my carer for working the day extra out of my own pocket, I buy more gadgets to see if can help me do things around the home as there is no-one around to assist, e.g. I need two picky up grabber sticks cause if I drop it I need another one to pick the first one up…….. Any DIY or odd jobs even changing a light bulb I have to pay for someone to come in ……. a full time partner or carer or if I had family would do these simple jobs free….

Generally local authorities in their assessments for charges take into account the SDP and DLA. Any disability related costs can be taken into account but these are generally very strictly interpreted so many extra costs that disabled people living on their own face are excluded from the assessment. Extra costs such as small house maintenance tasks or shopping would not be counted as a disability related cost.

This situation is likely to get worse rather than better as local authorities will not be able to take into account the SDP in deciding the level of charges and so will have even less to spend on social care when the SDP goes.

It should also be noted that the amount of support people were receiving varied enormously. A few mentioned support under the independent living fund and had fulltime carers however many of those who had said they received outside support explained that they had had a grant to pay for a one off piece of equipment or have a regular weekly session with a physiotherapist etc.

For example one respondent has 2nd progressive MS. They receive high rate mobility and mid rate care – they describe the extra costs they face preparing food, cleaning and in maintenance of their home as a result of living alone – they said they did not have a social life - the help they receive is:

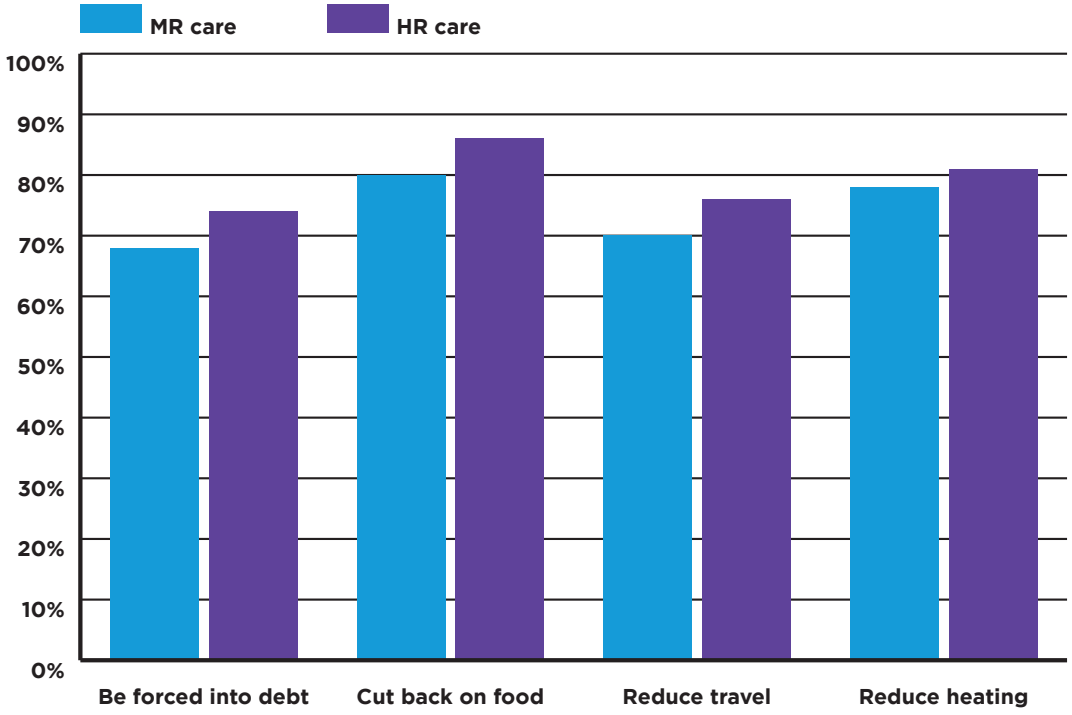
What would be the impact of a reduction in income

People were reminded throughout the survey that as long as their circumstances do not change they would be covered by transitional protection. They were asked what would be the impact of having to manage on £50 less income than they currently receive because they are in the strongest position to understand what will be the impact of this reduced level of benefit on someone who comes newly into the system. There were a number of options:

- Would be likely to get into debt
- Cut back on expenditure on leisure activities
- Cut back on expenditure on aids/equipment
- Cut back on food expenditure
- Reduce travel expenditure
- Reduce heating expenditure
- Find somewhere cheaper to live
- Other.

They were also asked them to elaborate in a free text box. Figure 2 below shows what people who would qualify for the SDP (on both the benefit criteria and being able to be treated as living on their own) believed would be the main impact of a reduction from current levels of income. It compares the predicted impact for those receiving the high rate and those receiving the mid-rate of the care component of DLA.

Figure 2: The predicted impact of the cuts



For those eligible for the SDP, 83% said a reduction in benefit levels of this amount would mean they would have to cut back on food and 80% said they would have to cut the amount they spent on heating. It is notable that whilst both groups felt this would clearly cut into essentials, those on the highest rate of the care component consistently recorded slightly higher levels of concern about cutting into essentials for each of

the possible impacts than those on middle rate care though it was only statistically significant that they reported an increased likelihood of getting into debt.

The textual answers really all fell into one category – things were already cut to the bone any extra cuts would cut even further into essentials. The following are just a very few of the examples of what they believed it would mean for someone in their position – as well as having to cut back on paying someone to care for them or to clean their home many people also mentioned doing without therapies which they believe make an important difference to their health. A number mentioned not being able to carry on living independently:

Level of care reduced and have health and safety implications. Live in cold house. Social life non existent. Not be able to afford travel costs. not be able to afford healthy diet

I would have to stop therapy. Everything else is already as mean as I can get it.

I would not be able to afford my frequent osteopathy. Going with out would mean not only more pain, but also increased suffocation and swallowing problems. My debts would increase. I would not be able afford my care or my special diet. My quality of life, already pretty poor would be hugely diminished.

I would clean the house perhaps once a month rather than once a week, and try to manage without a daily visit.

Cut backs on house cleaning but that would mean living in dirt

The thing that most worries me is not being able to afford heating in the winter. I am cold nearly all the time, and could not survive with less.

Cut back on transport, electricity, essential phone/Internet etc

I would have to give up my landline which is a dangerous thing to do as it is also a lifeline to my support network ….. I would not be able to pay my daughters fares to get to me to help me, thats even if I could communicate with her in the first place without a phone

I will end up spending even more time in bed as this will be the only way to keep warm as I will have to switch the heating down / off. i will have to look at whether I can cut down on the amount of paid help I receive - this means my house will get dirtier. I will not be able to get repairmen in to carry out little tasks - if the shower breaks, or the toilet breaks I will end up having to live with them broken!

I'd probably be out on the streets homeless! I already eat the most basic of diets & am very frugal with heating & electricity. I struggle to keep warm in winter & have to wrap up in extra clothes & blankets or stay in bed to keep warm I either eat a meal or have some heating on. I can't afford both.

I might have to move to residential care

It was clear throughout the survey the level of desperation many disabled people are feeling at the moment. The following is just one of a number of similar comments

I've thought about suicide as my quality of life has been so much reduced already (I've lost my job, friends and colleagues, exercise, social activities, holidays, life's little luxuries, I'm in pain every day etc etc). There has to be a point beyond which it's just not worth trying to stay alive - I can't imagine how someone in my situation would cope with less.

The evidence offered on the key questions

Is there evidence that the £58 currently paid to those who do not have a partner or carer is necessary?

In the current system as the government briefing on additions to Uc points out 'The Severe Disability Premium was introduced as a higher and additional premium for people living on their own (or treated as such) with high care needs not met by someone receiving Carer's Allowance'[1]. It would be reasonable therefore to end SDP without substitute only if its original rationale was flawed.

The overwhelming evidence from the responses was that people are struggling to manage on the income they have which for all those included in the above analysis would include as a minimum, means tested benefits including the SDP.

People were not directly asked if they had a social life – they were asked what was the extra cost of social activities yet almost half of those who commented specifically stated they had no or very little social life. They were having to prioritise other costs. Most of the rest explained what the cost would be without stating how often they actually saw other people socially.

For others paying for a cleaner and for a carer to help with the basic essentials of personal care were the two areas most prioritised but even there it was clear that many felt they were unable to pay for enough care to meet even the most basic essentials. Almost everybody who commented believed that any less income would have a devastating effect on their life and mean cutting back on essentials such as heating and food. Of those surveyed who fulfil the conditions to qualify as severely disabled and can be treated as living alone for the purpose of the SDP, 83% said that a cutback in benefit of this level would mean that they had to cut back on food and 80% said they would have to cut back on heating.

Does the evidence demonstrate that the restructuring which the government proposes will achieve its aim of supporting those with the greatest needs?

The government has stated that the restructuring of support for disabled people under UC has been designed to support those with the greatest needs. It has confirmed that the abolition of the SDP is not a money saving measure – all the money saved will be used to raise the level of the support component. However even when this is fully in place those in the support group who live on their own will still be considerably worse off under UC. The personal amount for someone on the support component is to be raised eventually to £151. Someone who has someone paid carers allowance to care for them currently receives £120. However someone who lives on their own and does not have a carer currently receives £178.

191 of the respondents were receiving the **highest rate of the care component of DLA and were living alone** and no one was paid carers allowance to care for them. This is the group who have been identified as having the highest level of care needs, only 43% were in receipt of any outside help but **only 15% received at least two hours of help a week**. The majority of even those receiving help with care clearly also faced many extra costs because they were unable to cook or clean their home or many of the very small tasks around the home that most people would do without thinking. It was clear that this group faced extra costs that those with a partner or someone paid carers allowance would not face. Many were very clearly struggling to manage on current levels of support.

The overwhelming majority of comments that were made indicated that these were people struggling on the edge. They were struggling to pay fuel bills. They commented frequently that they had no social life and had cut out any even small luxuries.

At the moment someone who is in the support group of ESA and lives on their own without a carer will receive £178 ESA (income related) plus their housing costs and their

1 http://www.dwp.gov.uk/docs/ucpbn-1-additions.pdf

DLA. Even when the government's aspiration is reached those in the support group who live on their own will receive £150 - £28 less than those in that position now.

We believe that in so far as it is possible to generalise at all - this group who are on the high rate of the care component of DLA and in the support group and in addition bear all the additional costs of a disabled person living on their own are the group with the greatest needs. The government has promised to protect those with the greatest needs. We believe abolishing the SDP goes against that principle.

Does the evidence demonstrate that those who live on their own face extra costs compared to someone, with a partner or someone paid carers allowance to care for them?

Separating out the extra costs a disabled person faces because they live on their own clearly involves some areas which are not clear cut – most disabled people with a partner would clearly want the means to travel independently when they wished but on the other hand the majority of disabled people in a couple with an able bodied partner would not need to pay for a taxi every time they went out of their home. Having to pay for very minor work on vehicles such as filling the wash bottles, having to pay someone to drive the vehicle are also costs which people with a paid carer or partner would probably not face.

Some extra costs however emerged very clearly, particularly in the areas of socialising and chores such as cooking, cleaning and house maintenance.

Nearly half the people who commented on the cost of social activities remarked in the free text box that they had no or very little social life, many others commented on the high cost of socialising without specifying how much of a social life they had. A number mentioned that in order to take part in a social activity there was not just the extra cost of transport but they also needed a carer to accompany them and would have to pay their costs as well. This made even a simple trip to a café prohibitively expensive. However even if they didn't have this extra cost people felt they had to prioritise other things. It is surely worrying that those most likely to be socially excluded because they live on their own felt unable to socialise because they could not afford it. This is likely to lead to a loss of confidence and will also have an impact on any possibility of them taking up work.

The other area where the extra costs of living on your own and without a carer emerged very clearly was the costs of household chores such as cooking and cleaning and very simple household maintenance tasks. This was an area of great concern to most of the respondents. Very many of the respondents had difficulty cooking and so were having to use ready meals which cost them more than cooking from scratch as well as being less healthy. Many felt they needed to prioritise paying a cleaner above other things such as socialising.

A lot of people remarked on the fact that there were many simple household chores and tasks such as changing a light bulb which if there were an able bodied person in the house they would do without thinking. There were many long lists of such jobs. One person remarked that he had to pay £10 for even the smallest of jobs. Others were paying for the petrol of relatives to travel from a distance to assist them. These relatives often lived too far away to qualify for carers allowance as they could not care for the length of time each week necessary to qualify but the money to pay their petrol was coming out of the benefits of the disabled person. It was clear that many were concerned that, because they were unable to do the maintenance tasks themselves and they could not afford to pay someone else to do it, their home was becoming very neglected.

The following charts compare the additional support under the current system and under UC for a disabled person with a partner who acts as a carer compared to a disabled person living alone or with a child carer.[2] It is clear that the most disadvantaged group – those in the support group and receiving the highest rate of the care component of DLA and living on their own will be worse off under UC.

2 This support is in addition to the basic amounts of living costs for a single person of £71 (the lone parent would also have a basic amount added to this for the living costs of their child) and for a couple of £111.

Figure 3: Disabled person receiving the mid rate of the care component of DLA and in the work related activity group showing the change between the current means tested system and UC in extra financial additions

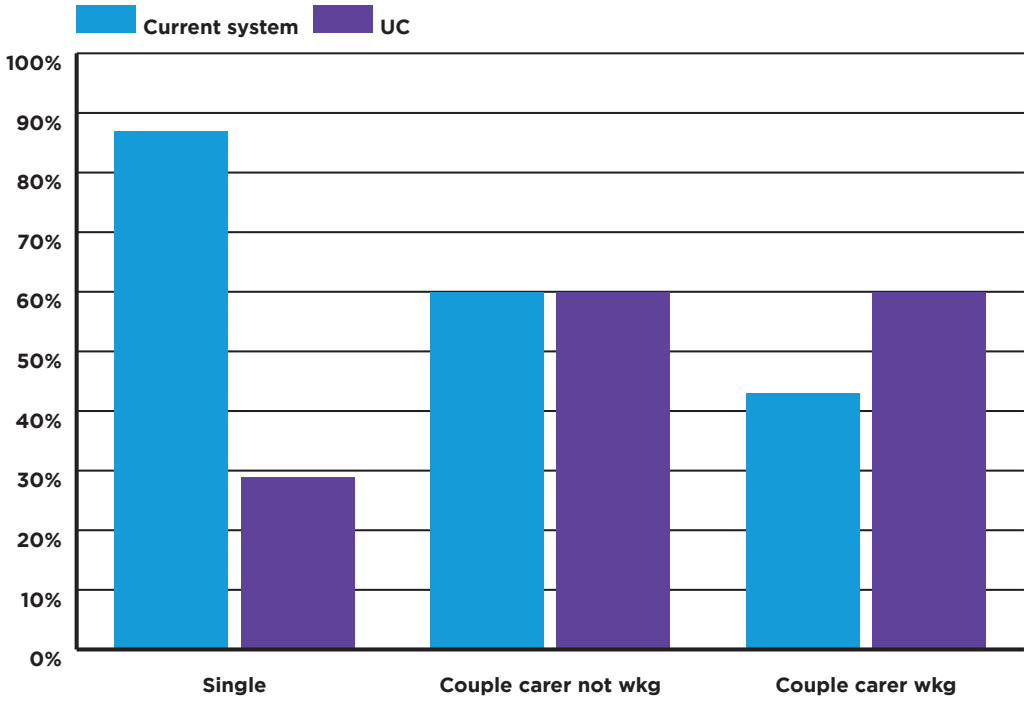
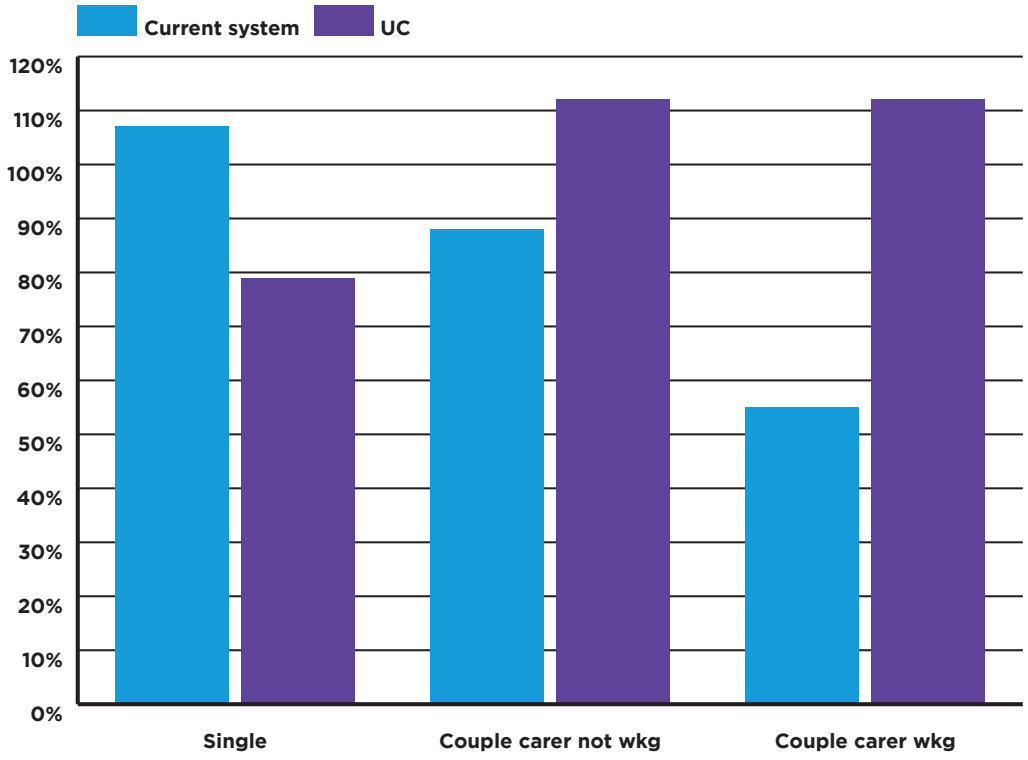


Figure 4: Disabled person receiving the high rate of the care component of DLA and in the support group showing the change between the current means tested system and UC in extra financial additions



This is a very significant transfer of additional support from single disabled people living on their own and lone parents with young carers to couples where one is disabled and the other partner is their carer (whether in or out of work).

Are any extra needs being met by outside agencies?

The government has argued that those who are living on their own will have their care needs met by social care provision. Of our respondents who would be eligible for the SDP[1] at present only 14% of those were receiving two hours or more of support a week from an outside agency. All of those eligible for the SDP would be entitled instead to have a carer paid carers allowance for 35 hours of caring. The 8% of those entitled to the SDP who were receiving 10 hours of care or more from an outside agency were having to pay part of their benefits towards their social care but many still faced extra costs for additional care and help with cleaning etc. which were not being covered by social care.

There was evidence that in particular minor household maintenance tasks which could be done by most people who were not disabled were never treated as a disability related expense and many other extra costs faced by a severely disabled person living on their own such as cleaning and cooking were frequently not covered by social care. It appeared to be very clear that the vast majority of those who live on their own and do not have someone paid carers allowance to care for them had many additional costs which were not being met by outside agencies and which would not be faced by those who did not live alone. Without the SDP they would have no income to meet these additional costs.

Anyone caring for at least 35 hours a week for someone who receives the middle or higher rate of the care component of DLA can claim carers allowance. The carers allowance means that the carers premium is added onto any means tested benefits claimed. This care is often provided by the disabled person's partner and can be absolutely vital in ensuring a decent quality of life and enabling the disabled person to take a more active role in society than would otherwise be possible. However the current system recognises that the single person living on their own without someone paid carers allowance for caring for them does not receive this support and is therefore at much greater risk of having unmet needs and being socially excluded. It compensates for this to some extent by adding the severe disability premium to the means tested benefits of this group.

People who live on their own and have no one paid carers allowance to care for them are of course in a variety of different circumstances. Whilst many were leading very isolated lives and having to pay professionals for any extra help they received, some disabled people who lived on their own and did not have a carer had a network of support from family and friends – none of whom were able to spend enough hours with the disabled person to claim carers allowance (usually because they lived at a distance) but our evidence showed that it was important to the disabled person's independence and self respect that they were able to pay at least the expenses such as the petrol of these people as they were not receiving carers allowance and to give small gifts to neighbours who helped out.

A chart showing the financial impact of the changes for different groups can be found in the appendix.

What evidence is there of the likely impact on people's lives of the abolition of the SDP?

We believe there is very strong evidence that those who live on their own and do not have a carer are facing higher costs than those who have a partner or someone paid carers allowance to care for them. Those who do not have a carer have to either pay a private carer or pay the expenses of a network of friends and family or if they receive a care package from social services contribute part of their benefits towards the cost. However it was clear that most weren't receiving any outside care and even of those who were receiving social care, the vast majority were only receiving care covering the basic essentials of personal care and were having to contribute out of their benefits leaving less available to cover other extra costs.

1 On the grounds of mid or high rate care of DLA and living alone or being able to be treated as if they live alone though not necessarily on the grounds of income

This was clearly causing enormous hardship currently. Many respondents were feeling desperate about their situation and were already saying they could not afford to have any social life. The evidence we have received shows that many are already struggling to manage on the income they currently have. **83% said that a cut in benefit of this level would mean they had to cut back on food expenditure and 80% said they would have to cut back on heating. As shown above the abolition of the severe disability premium cannot fail to cause much greater suffering and social exclusion.**

Is there a way in which extra support can be given to disabled people living on their own whilst not making UC more complex?

Simplification of the system is clearly a 'good thing' but any means tested system needs to target support at those who need it most. The DWP briefing on additions points out that the SDP has been difficult to administer and the cause of significant error. Advice agencies are certainly aware of the difficulty that DWP has had in correctly identifying when someone is entitled to the SDP and claimants have had understanding the criteria for the SDP. This is commonly caused by the confusion over the need for multiple reporting to different departments and coordination between those departments. In UC all household changes will need to be reported to just one department which could resolve this issue if the SDP were to be retained which would be our preferred option.

However in our recommendations we have also made an alternative recommendation which is to pay a self-care premium at the same rate as the carers premium. This we believe would answer any remaining issues over simplification and would not be difficult to administer. It would mean some reduction in the extra support offered and we see no evidence that this is justified. However we recognise that it is very unlikely that the SDP will be retained and we believe that a self-care premium would be very easy to integrate into UC and so has the best chance of success.

Extra costs for households with young Carers

Background

The SDP plays an essential role in supporting young carers. If a lone parent is severely disabled (or a couple where both are severely disabled) and their child acts as carer, the child cannot claim carer's allowance but the family can benefit from the extra financial help offered by SDP which takes some of the burden off the young carer.

The DWP reports that 25,000 lone parents are currently in receipt of the SDP.

Under UC a couple, where one person is in receipt of DLA mid rate or high rate care and the other works and also acts as a carer, will still keep the carers addition worth £33 even if the carer is working more than the current part-time limit so these households **will be more than £33 better off.**

However if that partner leaves and the children have to take on more of the caring role and the lone parent faces greater expense to cover those jobs the children cannot do then under UC the household will lose the £58 SDP they receive under the present system and will not be entitled to the carers premium leaving **these households £58 worse off than under the current system.**

Government rationale

The government argues that the children should not be doing the caring. However a majority of the severely disabled lone parents (and couples where both are disabled) in our survey were not receiving any help from outside agencies. Only 36% of households with children, but no adults, without a disability had support from other agencies. It was clear that households with young children were much more likely than disabled people living on their own to have outside help - 65% of households with children under 10 years and no child older than 10 years had outside help. This reflected the extra needs for care of the child(ren) as well as the disabled parent, and was especially true where the children were very young:

(A carer comes in) to ensure that my son is up, dressed, breakfasted, taken and collected from school, fed and put to bed.

However households with children 10 years or over were much less likely than a single disabled person living on their own to have outside help. Only 27% of households with a dependent child over the age of 10 years had any outside help whereas 37% of disabled adults living on their own had some outside help.

It is clear that the assumption being made is that a household with young children need additional support to help look after the children as well as the disabled parent. However if the child is over 10 then the assumption appears to be being made that the household needs less help because the child can act as the carer.

The woman described below is a lone parent with two children aged 13 and 14 and is receiving the high rate of the care and mobility component of DLA. Since she has no outside help her children are doing the caring:

I have been fighting adrenal cancer since 2006, diagnosed 2010..... I have had two major operations in the last 18 months and three monthly scans and all follow up appointments. I continued work until the beginning of 2009 when I could no longer go on to avoid the benefits system. My husband also left at this point and I was pushed out of my job. ...Daily I am very slow , constantly feel ill, fatigued, aching , struggle to concentrate, cannot function more than what I consider to be about 10% of pre illness.

It was very clear from the survey that the children were taking on a very significant caring role. 40% of respondent's children were spending more than 15 hours a week assisting their parents and 60% were spending more than 10 hours a week.

This was for all the respondents in the survey who had children of any age. 70% of households with at least one child aged over 10 or over were assisting their disabled parent for more than 10 hours each week. It is already having an impact on the life chances of these children as this mother of a 17 year old boy who is still at school points out:

My local authority no longer provides home care and I need to pay them for personal care. .....My son cannot cope with school and my needs and care for the home as well - his likelihood of obtaining his highers this year are nil. His whole future has been ruined because of our circumstances

If these families have their income cut by £58 it is clear that there will be even less money available, for example to employ a cleaner for a few hours a week. The following charts show for the different tasks, the percentage of children who spent more than an hour a week carrying out the various tasks and the percentage who spent more than four hours a week. These charts are for all the children so the percentages include very young children as well as teenagers.

Figure 5: Percentage of children assisting in specific tasks for more than one hour a week

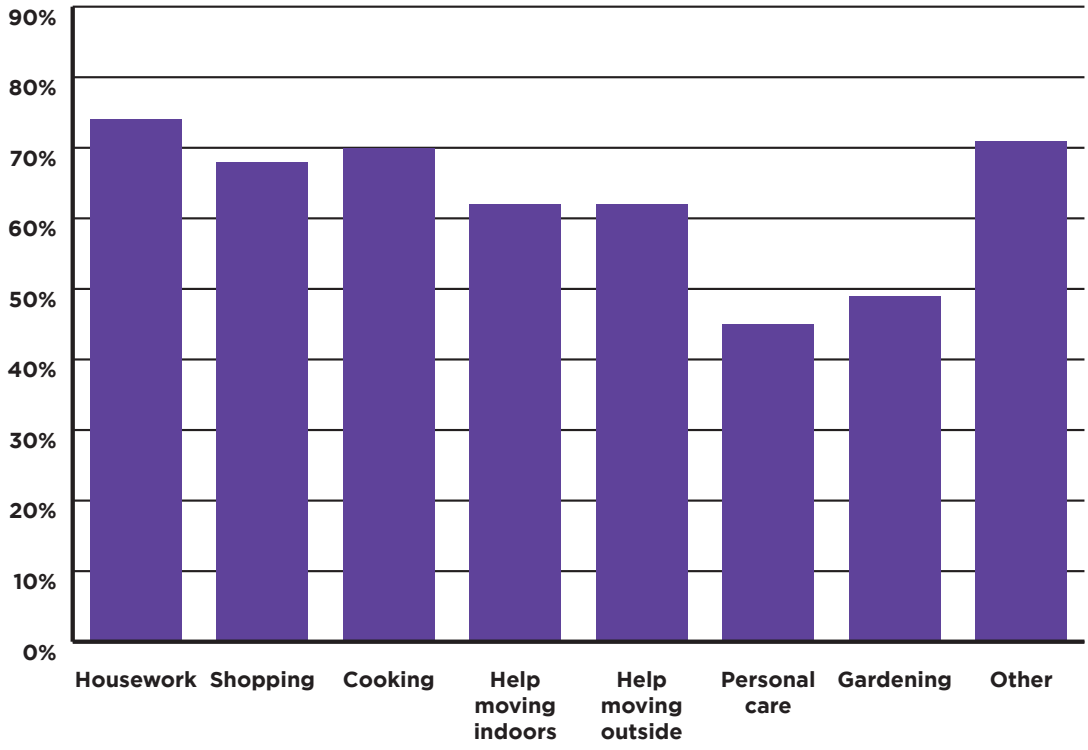
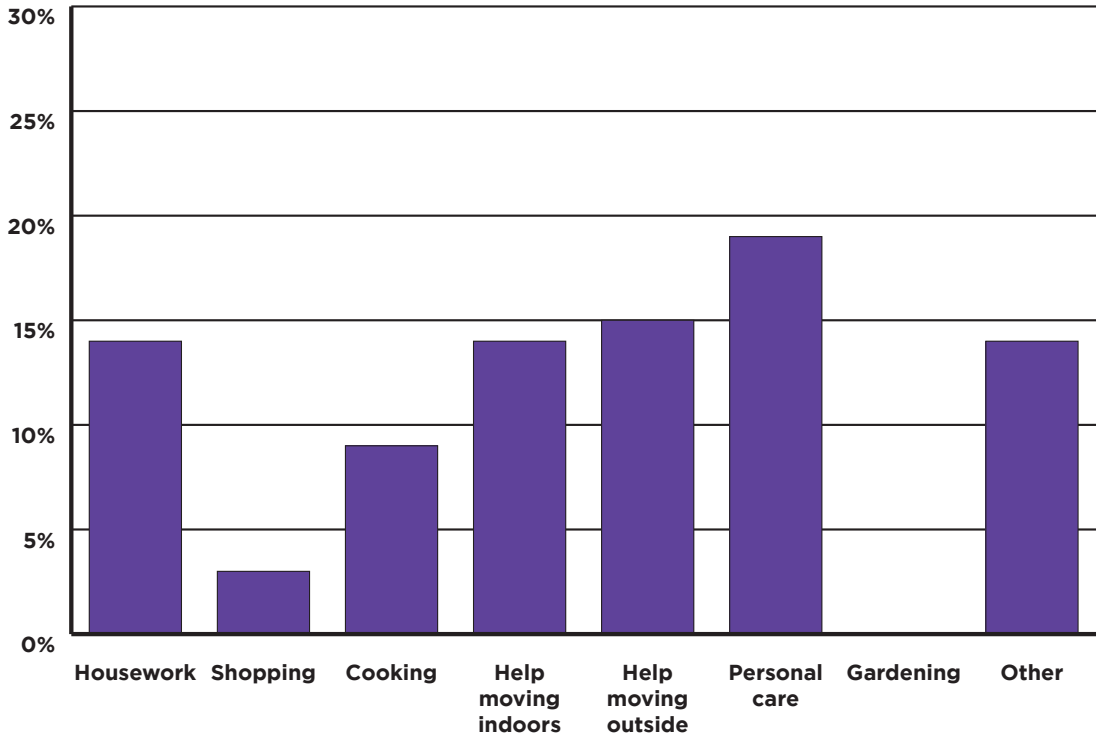


Figure 6: Percentage of children helping for more than four hours on each task



Help with personal care followed by help moving around outdoors and indoors, and housework were the tasks in which the greatest percentages of young carers spent more than four hours a week helping.

There were also particular extra costs that households with children faced in addition to those costs which are faced by disabled people living on their own. They had extra transport costs connected with essential trips for their children as well as themselves:

I pay people to, ...take my son to nursery, ...

Pay for child minder to collect child to and from school. ...

if I did not have someone to help by driving me about and take my children to and from school. I have to help these people travel to me. These are on going costs.

transport to everywhere includes taking children to Drs .....

Whilst many of those who lived on their own had reached a point where they had no social life because they could only afford to go out for essentials such as visits to the GP or hospital or shopping, those with children were in a different position. They were clearly concerned to try to limit the social exclusion of their children. Some of the witnesses at the evidence session mentioned their fears that children are unable to socialise due to their role as young carers. One of the witnesses at the evidence session has a 10 year old son who is a young carer for her. Taxis are essential to ensure her son is able to meet with friends, go to social/sport activities and attend a young carers group. She is concerned that if they saw a cut in their benefit support, her son may face greater social isolation.

A number of others in the survey also made this point:

Well the school summer holidays are coming up soon and I am going to have to pay to find people to take my children out throughout it as I can't keep them cooped up inside for that time it's not fair on them

I have to pay a lot for my child to do extra activities as I don't get to do as much as I like with him, so he does things to keep him occupied

For households with young carers it is clear that these parents were already feeling distressed that their children are having to take responsibility for so much of the caring and household jobs. The effect of taking £58 out of the household budget of families such as these must mean that children have to do even more. For parents there was also a strong fear that their children would face social exclusion if they had any less income. Preventing this was a key priority for the parents in our survey.

Conclusion

There is no rationale for not paying at least an equivalent of the carers premium to a disabled person living on their own and without someone paid carers allowance to care for them. Our evidence clearly shows much greater costs for this group and that the current extra paid through the SDP is not meeting the need. Under UC the proposal is to abolish this extra addition of the SDP, which went part way to covering these extra costs, and use the savings to redistribute it to all those in the support group, including those who do not face these additional costs. This means that the group who are likely to be most disadvantaged – those who are in the support group and who live on their own and do not have a carer will receive £28 less than currently even when the government reaches their target amount for the support group.

There is also no rationale for reducing the support for households with young carers by up to £58 a week The government argues that young carers should not be taking on a caring role. However it is clear that in the majority of cases children in this situation, especially when they reach teenage years, are already having to take on this role. If the income of households in this position in the future is reduced by £28 or £58 a week the children will inevitably have to take on more of the responsibilities as there will be less money available to pay for example for a cleaner for a few hours a week. The children are also likely to become more socially excluded. Under UC a household where one of the couple works but is also a carer will gain an extra addition of £33 and the household with the child who goes to school but is also a carer will lose the £58 addition.

The evidence we have received shows the majority are already struggling to manage on the income they currently have. The abolition of the SDP cannot fail to cause much greater suffering and social exclusion

Recommendations

Our preferred option would be to retain the severe disability premium as it is. We believe there is clear evidence that the money which severely disabled people who live on their own and do not have a carer currently receive is a basic minimum. This group has extra costs which are not faced by those who have a partner or a carer. Whilst it has caused some administrative difficulty in the past because of reporting requirements to different departments, we think it could work in a much more straightforward way under UC because there is only one agency to which to report all changes.

A simpler option would be to award a self-care premium paid at the same rate as the carers premium to anyone who does not have anyone claiming the carers allowance or the carers premium. This would obviously be a slightly wider group than the current SDP because an adult son or daughter coming to stay would under the current rules stop the SDP and this has often caused problems when adult children have come in and out of the property. However this is likely to be a fairly minimal impact on the overall cost especially as they will be able to claim the carers premium themselves, even if they are working.

Appendix 1. Descriptions of key benefits

Disability Living Allowance (DLA)

DLA is paid to help with disabled people's care or mobility needs. It is paid to children and to adults of working age. Adults of pension age can claim Attendance Allowance. There are two different components in DLA 'care' and 'mobility'.

Disabled people can receive **the care component** at one of three rates, low, middle and high depending on the frequency of their needs for personal care. To receive the high rate someone must need frequent help with personal care both day and night.

Disabled people can receive **the mobility component** at one of two rates. The low rate is for someone needs guidance or supervision to go somewhere unfamiliar. The highest rate is generally only payable to those who have very significant difficulties walking.

Employment and support allowance (ESA)

ESA is a benefit paid in replacement of earnings for those who are unable to work because of an impairment or health condition. People are assessed through the work capability assessment (WCA) to determine the extent to which their ability to perform certain tasks is limited by a health condition or impairment and awarded points on this basis. This assessment will determine whether someone receives ESA and at what rate. There are three possible outcomes from the assessment:

- Someone who receives less than 15 points **will not be awarded ESA** and will be expected to look for work immediately eg someone who cannot walk 100 metres without stopping but has no other impairment will be awarded nine points.
- Someone who receives 15 points or more will be placed in the **work related activity group (WRAG).**
- Those with the highest level of impairment will be placed in the **'support group**'.

For the purposes of the SDP and carers allowance a 'severely disabled person' is defined by the current benefits system as someone who receives either the high rate or the mid rate of the care component of DLA.

Severe Disability Premium (SDP) is only payable to those on the lowest incomes as it is an addition which increases the level of means tested benefits for 'severely disabled' people in and out of work. They must also either live on their own or just with dependent children and have no one who is paid carers allowance to assist them. They can also receive it if they live with another disabled person who would also be entitled to it if they lived on their own.

Carers Allowance – Within this report unless we stipulate 'paying for a carer' we use the word carer to mean someone who is paid the benefit (carers allowance) to assist someone who is 'severely disabled' at least 35 hours a week. The only other exception is in the case of young carers who are not eligible for this benefit.

Carers Premium – The carers premium is paid as an addition to any means tested benefits in the current system which are received by someone who has an entitlement to carers allowance. There will be a similar addition within UC. Under the current system if someone earns more than £100 a week they lose entitlement to the carers premium. Under UC there will be no earnings limit.

Appendix 2

Table showing the amount of extra financial additions in the current means tested system and under Universal Credit, for severely disabled people who live on their own and to a single disabled person who is part of a couple with a partner as their carer.

Level of benefits of disabled person	Single person living on own		Couple - one partner is disabled – the other is their carer and doesn't work or works part-time earning no more than £100		Couple - one partner is disabled – the other is their carer but also works fulltime	
	Current system	Universal credit	Current system	Universal credit	Current system	Universal credit
Work related activity group (WRAG) & mid rate care of DLA	£28 WRAG comp[15] + £58 SDP[16] **Total £86**	£28 WRAG comp **Total £28**	Support comp starting at £49 Rising to £79 **Total £79**	£28 WRAG comp & £33 carer premium **Total £61**	£43 dis premium **Total £43**	£28 WRAG comp & £33 carer prem **Total £61**
Support group & mid rate care of DLA	£34 support comp £15 EDP[17] & £58 SDP **Total £107**	Support comp starting at £49[18] Rising to £79 **Total £79**	£34 support comp £21 EDP + £33 carer premium **Total £88**	Support comp starting at £49 Rising to £79 +carers premium £33 **Total £112**	£34 support comp £21 EDP **Total £55**	Support comp starting at £49 Rising to £79 +carers prem £33 **Total £112**

The amounts shown are in addition to the basic amounts of living costs for a single person of £71 and for a couple of £111.

15 Work related activity group component

16 Severe disability premium

17 Enhanced disability premium

18 We have made the assumption that when UC first rolled out those in the support group will receive the same as in the current means tested system ie £34 support component and £15 enhanced disability premium = total £49 as there will at that point be no savings from the planned cuts

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